Disability and Secondary Conditions

Chapter 6

Vision for the Decade:
Proceedings and Recommendations of a Symposium
Atlanta, Georgia, December 4–5, 2000

FOREWORD

Between the years 1900 and 2000 medical and public health advances allowed life expectancy to be extended by 30 years. Quality of life was also improved for many. A byproduct of these advances has been that many more people are living with disabilities. The growing emergence of this group has required us to rethink our concepts of health and disability. Today, the release of *Healthy People 2010* recognizes that this group of Americans can live healthy lives and participate equally in society. The inclusion of *Disability and Secondary Conditions* as one of the 28 chapters in *Healthy People 2010* highlights this perspective.

The two overarching goals of *Healthy People 2010* are to 1) increase the quality and years of healthy life for all Americans and 2) eliminate health disparities. These goals are particularly poignant for people with disabilities. The traditional notion that disability must naturally be equated with poor health is no longer tenable. Public health and medical care are expanding their paradigms to include health promotion and disease prevention in this population. In addition, people with disabilities often experience health disparities related to environmental barriers, including problems with physical accessibility, societal attitudes, and access to care. These proceedings provide a thoughtful starting point for addressing the lofty Healthy People goals.

The development of this new chapter has also generated extensive new partnerships. For the first time in the history of the Healthy People movement, a co-lead agency outside of the Department of Health and Human Services has been included. The National Institute on Disability and Rehabilitation Research in the US Department of Education has joined the Disability and Health group in CDC's National Center on Birth Defects and Developmental Disabilities to lead in this critical national effort to improve the health and well-being of people with disabilities across the life span. I am pleased that some 75 organizations, within and outside government, have contributed to developing this chapter. It is this kind of coalition that will be needed to achieve the ambitious targets set in these objectives.

I have long supported the inclusion of people with disabilities in the Healthy People process, and am pleased that we have come so far in this effort. I look forward to watching this coalition influence the health and disability policies, programs, practices, and science during the next decade.

David Satcher, M.D., Ph.D.
Surgeon General of the United States

EXECUTIVE SUMMARY

At its core, *Healthy People 2010* provides a vision for what we want to do, where we want to go, and who we want to be as a nation relative to health. It does not tell us how to do it. The overarching goals of *HP2010* indicate that what we want to do and where we want to go are expressed by: 1) increasing the quantity and quality of life for Americans, and 2) eliminating the disparities in health among us. Who we want to be is characterized by the principle of inclusion. This health agenda, for the first time, specifically addresses the health of Americans living with disabilities. *Disability and Secondary Conditions (Chapter 6)* outlines 13 objectives important to improving the health of people with disabilities. Working toward these objectives contributes to the larger vision of better health for all Americans.

It is usually easier to state an objective than to describe how to achieve that objective. This is particularly the case with new objectives. In order to begin the process, some 80 persons were invited to participate in one of 13 workgroups—one for each of the objectives in Chapter 6 of *HP2010*. A critical building block for meeting objectives in a new area is the development of alliances among partners. These individuals represented roughly 37 nongovernmental organizations and 25 universities, as well as public health staff for the states, and federal employees from health and education.

Each small group (5-7 people) answered five questions for each of the 13 objectives, including:
1. How practical are the targeted objectives for implementation by the year 2010?
2. What are the major problems in addressing this objective?
3. Who are the governmental, non-governmental, private, and other *Healthy People 2010* Consortium members who could/should be partners in implementing this objective?
4. What are initial programs, current or envisioned, and /or policies that could help meet this objective?
5. Are adequate mechanisms in place for tracking progress toward meeting the targeted objectives? If not, what needs to be done to institute such tracking mechanisms?

This volume includes the reference chapter *Disability and Secondary Conditions* (page 7), a synthesis of the workgroup information, an extended report of each workgroup's deliberations, and ends with an integrated set of next steps and appendices. It is clear that no brief overview can do justice to the extraordinary substance included in the individual reports. To provide some sense of the vitality and direction of the effort, however, we will highlight several general conclusions.
1. The objectives in chapter 6 are reasonable and can be achieved by the end of the decade. Considerably more human and financial resources will be needed for this to occur. In addition, an undergirding energy based on the strength of partnerships will be required.

2. Major problems will be faced, including:
   a. a <u>misunderstanding of disability</u> in the general population, devaluing the life experience of people with disabilities;
   b. <u>media messages</u> that contribute to a negative image of people with disabilities, resulting in poor self-concept and low self-esteem;

c. a continuing struggle to address <u>environmental barriers to societal participation</u> of people with disabilities;

d. no <u>organizational leadership</u> to assess barriers and address their elimination;

e. <u>technical problems</u>, including inconsistent definitions of core terms—perhaps especially "disability" itself—and the need for psychometrically-sound instruments;

f. <u>resource issues</u>, including the need for more financial and human resources, resource allocation problems associated with fragmented funding streams, inconsistencies of resource commitment across states, little incentive for the private sector to be involved in promoting the health of people with disabilities, and inconsistent insurance coverage for preventive services;

g. <u>service integration problems</u>, particularly associated with 1) school and health services, creating mental health issues for families, and 2) the mental health needs of people with disabilities, especially children; and, finally,

h. a lack of <u>training for professionals across disciplines</u> in disability dynamics and issues, especially the impact of environmental factors.

3. These problems, however, did not deter the groups from believing in the viability of the objectives. The workgroups' consensus is that the only way to meet the targets of the objectives is to build effective coalitions. Members of the coalitions will need to focus on the contribution they can make to the larger good reflected in the objectives. The organizations will be local through international, small to mega-large, formal and informal, health care and health-related organizations. All sectors of the disability community will be needed, alongside organizations not usually associated with the disability community, such as architects, city planners, and private industry.

4. The programs and policies (current or envisioned) that provide the substance for addressing the objectives include broad social changes and narrow, almost individual, interventions. Some of the directions include:

a. educating the public and media to understand the experience of disability;

b. using the *International Classification of Functioning, Disability, and Health (ICF)* gives a conceptual framework for understanding the interaction of the person and the environment, as well as providing a classification system for data on the dimensions of the disability process;

c. encouraging ratification of the United Nations Convention on the Rights of the Child, and acknowledging the shared responsibility toward children and families;

d. extending Early Intervention programs to transition times for children—beginning school and adolescence, and leaving school;

e. expanding clinical interventions for mental health needs, and encouraging community connections to meet social needs of people with disabilities;

f. pressing for community-based placements for children and adults in congregate care facilities;

g. advocating for full accessibility of school, workplace and public accommodations so that education, employment, and societal participation are increased, improving quality of life;

h. reviewing all policies and economic-related practices within government that impact the health and well-being of people with disabilities to ensure that they encourage,

rather than discourage, full participation; and establishing standards, guidelines, and policies to facilitate inclusion;

i. educating and training professionals across disciplines about disability issues;

j. assessing and supporting the health of caregivers; and

k. implementing programs in every state, territory, and tribe to promote the health and well-being of people with disabilities.

5. Workgroups indicated that data sets currently in place to measure the progress toward objectives are adequate. However, no workgroup was satisfied with the status of data, and more work is needed to ensure strong data for monitoring the objectives.

The activities generated in this symposium were intended as the first step in the *HP 2010* strategic planning and implementation process. They will be followed by a larger working conference of key stakeholders to generate, mobilize or support alliances and coalitions. The purpose of that exercise will be to identify programs and policies to be targeted, to specify the actions needed to launch new programs/policies or revise existing programs/policies, to establish priorities for action, and to recommend appropriate administrative and logistical support needed to implement the plans.

This set of workgroup reports was meant to ensure that all objectives would have individual attention. The next step will allow participants to focus attention on broader themes. For example, the themes outlined in the Synthesis chapter of this volume (page 49) include data, children, social/emotional health, societal participation, accessibility/environment, and caregiving/long-term care. Specific activities could be addressed within each thematic area, emphasizing coalition building, legislative/policy initiatives, research, public/professional education and training, and data issues.

The next 10 years are pivotal; the current vision and energy will have been focused and harnessed, or an opportunity will have been lost. The current momentum will be used to eliminate health disparities that exist and increase the quantity and quality of life for Americans with disabilities. This document provides the foundation for change.

Donald J. Lollar, Ed.D.
Atlanta, Georgia
June 26, 2001

INTRODUCTION

Healthy People 2010
Chapter 6: Disability and Secondary Conditions

Goal

Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population.

Overview

Because disability status has been traditionally equated with health status, the health and well-being of people with disabilities has been addressed primarily in a medical care, rehabilitation, and long-term care financing context. Four main misconceptions emerge from this contextual approach: (1) all people with disabilities automatically have poor health, (2) public health should focus only on preventing disabling conditions, (3) a standard definition of "disability" or "people with disabilities" is not needed for public health purposes, and (4) the environment plays no role in the disabling process. These misconceptions have led to an underemphasis of health promotion and disease prevention activities targeting people with disabilities and an increase in the occurrence of secondary conditions (medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences).

Issues

Challenging these misconceptions will help to clarify the health status of people with disabilities and address the environmental barriers that undermine their health, well-being, and participation in life activities. A broad array of health promotion activities are relevant to all people experiencing a disability, whether they are categorized by racial or ethnic group, gender, and primary conditions or diagnoses, such as major depression, cerebral palsy, diabetes, spinal cord injury, or fetal alcohol syndrome. The similarities among people with disabilities are as important as or more important than the differences among clinical diagnostic groups. Caregiver issues also have been considered, as well as environmental barriers. Environmental factors affect the health and well-being of people with disabilities in many ways. For example, weather can hamper wheelchair mobility, medical offices and equipment may not be accessible, and shelters or fitness centers may not be staffed or equipped for people with disabilities. Compliance with the Americans with Disabilities Act (ADA) would help overcome some of these barriers. A crosscutting goal is to eliminate disparities with the nondisabled population.

The *International Classification of Functioning and Disability (ICIDH-2),* developed by the World Health Organization (WHO) with the input of numerous nations—including the United States—provides uniform language and a framework for describing functioning, health, and disability status among all people.[1] This framework clarifies definitional issues and includes environmental factors.

Trends

An estimated 54 million persons in the United States, or nearly 20 percent of the population, currently live with disabilities.[2] Data for the period 1970 to 1994 suggest that the proportion is increasing.[3] The increase in disability among all age groups indicates a growing need for public health programs serving people with disabilities.

From 1990 to 1994, disability rates increased among youth under age 18 years.[3] There was a 33 percent increase in activity limitations among girls, from 4.2 percent to 5.6 percent, and a 40 percent increase in activity limitations among boys, from 5.6 percent to 7.9 percent.

Among adults aged 18 to 44 years, there was a 16 percent increase in activity limitations, from 8.8 percent in 1990 to 10.3 percent in 1994.[3] This increase suggests that 3.1 million more people aged 18 to 44 years were limited in 1994 than in 1990.

The absolute number of adults aged 65 years and older with disabilities increased from 26.9 million in 1982 to 34.1 million in 1996. Because the total number of adults aged 65 years and older increased even faster, the proportion of those with disabilities declined from 24.9 percent in 1982 to 21.3 percent in 1994.[3] However, the rise in numbers indicates a growing need for programs and services to serve this older population.
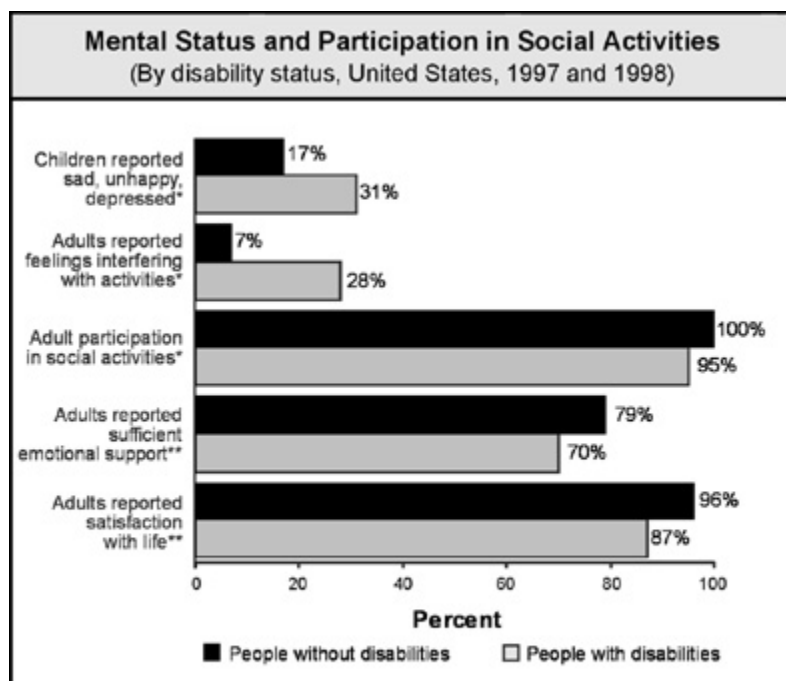
The direct medical and indirect annual costs associated with disability are more than $300 billion, or 4 percent of the gross domestic product.[4] This total cost includes $160 billion in medical care expenditures (1994 dollars) and lost productivity costs approaching $155 billion.

The health promotion and disease prevention needs of people with disabilities are not nullified because they are born with an impairing condition or have experienced a disease or injury that has long-term consequences.[5] People with disabilities have increased health concerns and susceptibility to secondary conditions. Having a long-term condition increases the need for health promotion that can be medical, physical, social, emotional, or societal.

People who have activity limitations report having had more days of pain, depression, anxiety, and sleeplessness and fewer days of vitality during the previous month than people not reporting activity limitations.[6] Increased emotional distress, however, does not arise directly from the person's limitations. The distress is likely to stem from encounters with environmental barriers that reduce the individual's ability to participate in life activities and that undermine physical and emotional health. In view of the increased rates of disability among youth, it is particularly important to target activities and services that address all aspects of health and well-being, including promoting health, preventing secondary conditions, and removing environmental barriers, as well as providing access to medical care. For an older person with a disability, it is important to target worsening coexisting conditions that may intensify and thus threaten general well-being. For example, declining vision combined with declining hearing can greatly impair mobility, nutrition, and fitness.[7]

Disparities

Disability can be viewed as a universal phenomenon everyone experiences at some time.[8] Disability also can be viewed as representing a minority of the population, in that people with disabilities may be less visible, undercounted, and underserved.[9] As a potentially underserved group, people with disabilities would be expected to experience disadvantages in health and well-being compared with the general population. People with disabilities may experience lack of access to health services and medical care and may be considered at increased risk for various conditions.

Mental Status and Participation in Social Activities
(By disability status, United States, 1997 and 1998)

	People without disabilities	People with disabilities
Children reported sad, unhappy, depressed*	17%	31%
Adults reported feelings interfering with activities*	7%	28%
Adult participation in social activities*	100%	95%
Adults reported sufficient emotional support**	79%	70%
Adults reported satisfaction with life**	96%	87%

Sources: *CDC, NCHS. National Health Interview Survey (NHIS), 1997.
**CDC, NCCDPHP. Behavioral Risk Factor Surveillance System (BRFSS), 1998.

Few data systems identify people with disabilities as a subpopulation. Disparities need to be identified to plan appropriate public health programs. Despite the paucity of data, some disparities between people with and without disabilities have been noted. These disparities include excess weight, reduced physical activity, increased stress, and less frequent mammograms for women over age 55 years with disabilities.[10]

Opportunities

Health promotion programs that focus on improving functioning across a spectrum of diagnoses and a range of age groups are effective in reducing secondary conditions and outpatient physician visits among people with disabilities.[11], [12], [13] For example, a focus on improving muscle tone, flexibility, and strength can accrue benefits for mobility-impaired people in

wheelchairs and mobility-impaired people with arthritis.[14] For people with communication disabilities and disorders, interventions can improve access to health-enhancement programs. People with sight impairments can have access to readable job applications, food labels, and medications. People with hearing impairments can have access to televised or videotaped exercise programs that are captioned or signed by interpreters depicted within an inset of a video screen. Often, the most effective interventions may be environmental rather than medical.

Many health promotion interventions already in place for the population at large may be easily adapted to the needs of people with disabilities. New strategies can be influenced by results from studies that describe risk factors for secondary conditions or protective factors against additional impairments. For example, the number of cases of secondary osteoporosis among able-bodied women and their range of bone mineral density deficits can be estimated by using existing Federal data sets. The degree to which women exercise and ingest calcium or estrogen supplements also can be estimated, leading to measurements of the influence of both risk and protective factors associated with osteoporosis in the able-bodied population. Because women with mobility impairments experience an elevated risk for secondary osteoporosis at earlier ages, their risk factors, including diminished bone mineral density, and their potential protective factors, including optimal calcium or estrogen supplementation and types of exercise, become critically important epidemiologic parameters.[15], [16] The results of investigations of secondary osteoporosis already influence health promotion strategies among able-bodied women. Similar investigations can augment the development of health promotion strategies among women with disabilities.

Current guidelines provide opportunity to design health promotion interventions targeting people with disabilities that accommodate ongoing evidence-based evaluation[17] and demonstrate cost-effectiveness.[18], [19] For example, clinical interventions that focus on appropriate and timely medical care can be equally accessible for people with and without disabilities. Mammography screening is recommended every 1 to 2 years, with or without an annual clinical breast examination, for able-bodied women aged 50 to 69 years.[20] This recommendation also can be adapted for women with disabilities. Clinical providers, however, must first recognize the reasons women with disabilities often refrain from seeking mammography services, such as the lack of adaptive equipment on mammography screening machines or unfamiliarity with the needs of people with disabilities expressed by clinicians. Counseling to prevent injuries among all adults also is recommended. For example, men and women with disabilities, especially those with skeletal insufficiencies or calcium deficits, are at increased risk for fractures. Adding bone mineral screening and fitness counseling during clinical encounters may be beneficial in preventing injuries. In these ways, evidence-based health promotion and disease prevention programs can be developed, implemented, and evaluated to target the health and injury disparities between people with and without disabilities.

Health promotion interventions for people with disabilities—in the community, clinical settings, or elsewhere—should include culturally and linguistically appropriate elements.

Interim Progress Toward Year 2000 Objectives

Healthy People 2000 did not have a chapter specifically establishing health objectives for people with disabilities. However, some objectives targeted people with disabilities, including leisure-time physical activity, use of community support programs by people with severe mental disorders, treatment for depression, activity limitations associated with chronic conditions and back conditions, and receipt of recommended clinical preventive services. A progress review held in January 1997 showed that none of these specific objectives relevant to people with disabilities had been met,[10] and parity with the nondisabled population will continue to be monitored.

People with disabilities reporting no leisure-time physical activity declined from the 1985 baseline of 35 percent to 29 percent in 1995, short of the target of 20 percent for 2000. In addition, the review noted several disparities: 40 percent of people with disabilities aged 20 years and older reported being overweight compared with 35 percent of the general population and short of the goal of 25 percent; 49 percent of people aged 18 years and older with disabilities reported adverse health effects from stress compared with 34 percent of the general population; and clinical preventive services showed disparities for data on tetanus boosters (56 percent versus 59 percent for the general population), Pap tests (69 percent versus 77 percent of women aged 18 years and over in 1994), and breast exams and mammograms (50 percent versus 56 percent for women aged 50 years and over).

Note: Unless otherwise noted, data are from the Centers for Disease Control and Prevention, National Center for Health Statistics, *Healthy People 2000 Review, 1998–99.*

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Disability and Secondary Conditions

Goal: Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the US population.

Number	Objective Short Title
6.1	Standard definition of people with disabilities in data sets
6.2	Feelings and depression among children with disabilities
6.3	Feelings and depression interfering with activities among adults with disabilities
6.4	Social participation among adults with disabilities
6.5	Sufficient emotional support among adults with disabilities
6.6	Satisfaction with life among adults with disabilities
6.7	Congregate care of children and adults with disabilities
6.8	Employment parity
6.9	Inclusion of children and youth with disabilities in regular education programs
6.10	Accessibility of health and wellness programs
6.11	Assistive devices and technology
6.12	Environmental barriers affecting participation in activities
6.13	Surveillance and health promotion programs

6-1. **Include in the core of all relevant Healthy People 2010 surveillance instruments a standardized set of questions that identify "people with disabilities."**

Target: 100 percent.
Baseline: No Healthy People 2010 surveillance instruments include a standard set of questions that identify people with disabilities in 1999.
Target setting method: Total coverage.
Data source: CDC, NCEH.

The call for statistics on people with disabilities is longstanding and increasing. Various Federal agencies have attempted to collect these data in several research areas.[21] Two separate issues exist regarding data collection: (1) using different operational definitions of disability and (2) not collecting information from people with disabilities during surveys. None of the federally funded surveys attempting to collect data on people with disabilities is using the same definition of disability. This lack of standardization has made it difficult to (1) identify and include individuals with a disability, (2) measure the nature and extent of disability in the United States, (3) assess the impact of various disabilities on the person's ability to participate in society, (4) assess the extent of secondary conditions among people with disabilities, and (5) identify environmental barriers to participation and risk factors for poor health in this population.

The issue of not including people with disabilities is reflected in the initial survey design. Most studies are not designed to include, target, and analyze data on people with disabilities. People with disabilities could be included as a select population if, for example, the data collection method ensured appropriate access and outreach.

To remedy these gaps, a set of survey questions has been developed and is being tested to identify individuals with varying degrees of disability in terms of activity limitations.[22] This short set of questions may be placed in the core of all Healthy People surveillance instruments that collect demographic data to include and standardize information on people with disabilities. On the basis of standardization and inclusion in the Nation's disability data collection activities, the call for disability statistics may be satisfied. Once collected, these data will help government policymakers, consumers and advocates, researchers, and clinicians make better and informed choices to promote the health status and well-being of people with disabilities.

6-2. Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed.

Target: 17 percent.

Baseline: 31 percent of children and adolescents aged 4 to 11 years with disabilities were reported to be sad, unhappy, or depressed in 1997.

Target setting method: 45 percent improvement (parity with children and adolescents without disabilities in 1997).

Data source: National Health Interview Survey (NHIS), CDC, NCHS.

Children and Adolescents Aged 4 to 11 Years, 1997	Reported To Be Sad, Unhappy, or Depressed	
	With Disabilities	Without Disabilities*
	Percent	
TOTAL	31	17
Race and ethnicity		
American Indian or Alaska Native	DSU	DSU
Asian or Pacific Islander	DSU	13
Asian	DSU	16
Native Hawaiian and other Pacific Islander	DSU	DSU
Black or African American	DSU	16
White	31	17
Hispanic or Latino	32	16
Not Hispanic or Latino	30	17
Black or African American	DSU	17
White	31	18
Gender		
Female	32	16
Male	30	18
Family income level		
Poor	37	20
Near Poor	31	17
Middle/high income	27	17

Geographic location		
Urban	27	17
Rural	39	16

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.
*The total represents the target. Data for population groups by race, ethnicity, gender, socioeconomic status, and geographic location are displayed to further characterize the issue.

6-3. Reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness, or depression that prevent them from being active.

Target: 7 percent.

Baseline: 28 percent of adults aged 18 years and older with disabilities reported feelings that prevented them from being active in 1997 (age adjusted to the year 2000 standard population).

Target setting method: 75 percent improvement (parity with adults aged 18 years and older without disabilities in 1997).

Data source: National Health Interview Survey (NHIS), CDC, NCHS.

Adults Aged 18 Years and Older, 1997	Reported Feelings That Prevent Activity	
	With Disabilities	Without Disabilities*
	Percent	
TOTAL	28	7
Race and ethnicity		
American Indian or Alaska Native	22	15
Asian or Pacific Islander	30	7
Asian	DSU	6
Native Hawaiian and other Pacific Islander	DSU	14
Black or African American	31	8
White	28	7
Hispanic or Latino	40	9
Not Hispanic or Latino	27	7
Black or African American	31	8
White	27	6
Gender		
Female	30	8
Male	26	6

Family income level		
Poor	38	13
Near Poor	30	10
Middle/high income	21	6
Education level (aged 25 years and older)		
Less than high school	34	10
High school graduate	29	7
At least some college	25	5
Geographical location		
Urban	29	7
Rural	26	6

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.
Note: Age adjusted to the year 2000 standard population.
*The total represents the target. Data for population groups by race, ethnicity, gender, socioeconomic status, and geographic location are displayed to further characterize the issue.

Children and adults with disabilities and their families face issues of coping, adapting, adjusting, and learning to live well with the disability—a dynamic, ongoing process. Good mental health, including refusing to internalize the social stigma of disability and developing a positive attitude and strong self-esteem, is a key ingredient to overcoming these issues.[23] Improving mental health status among people with disabilities and their families will help address psychological barriers and enhance their ability to participate fully in society.[24]

6-4. Increase the proportion of adults with disabilities who participate in social activities.

Target: 100 percent.

Baseline: 95.4 percent of adults aged 18 years and older with disabilities participated in social activities in 1997 (age adjusted to the year 2000 standard population).

Target setting method: Total participation (parity with adults aged 18 years and older without disabilities in 1997).

Data source: National Health Interview Survey (NHIS), CDC, NCHS.

Adults Aged 18 Years and Older, 1997	Participation in Social Activity	
	With Disabilities	Without Disabilities*
	Percent	
TOTAL	95.4	100.0
Race and ethnicity		
American Indian or Alaska Native	87.4	100.0
Asian or Pacific Islander	99.6	100.0
Asian	99.5	100.0
Native Hawaiian and other Pacific Islander	100.0	100.0
Black or African American	95.0	99.8
White	95.6	100.0
Hispanic or Latino	93.9	100.0
Not Hispanic or Latino	95.5	100.0
Black or African American	95.0	99.8
White	95.7	100.0
Gender		
Female	95.2	99.9
Male	95.7	100.0
Family income level		
Poor	93.1	99.9
Near Poor	95.8	99.9
Middle/high income	96.5	100.0
Education level (aged 25 years and older)		
Less than high school	94.1	99.9
High school graduate	94.8	99.9
At least some college	96.0	100.0
Geographic location		
Urban	95.3	100.0
Rural	95.6	99.9

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.
Note: Age adjusted to the year 2000 standard population.
*The total represents the target. Data for population groups by race, ethnicity, gender, socioeconomic status, and geographic location are displayed to further characterize the issue.

People with disabilities report significantly lower levels of social participation compared with people without disabilities.[25] Participating in social activities routinely requires personal interaction with the environment, a component of life that is vital to the well-being of all humanity. ICIDH-2, the *International Classification of Functioning and Disability,* highlights the importance of participating in social activities as a measurable outcome of living well with a disability.[1] The ICIDH-2 framework indicates that the environment should be examined as a barrier to participation.

Social participation can include activities such as volunteering, shopping, going to the movies, or attending sporting events. Targeting increased participation in regular social activities such as traveling, socializing with friends and family, attending church or community events, and voting can result in improved functional status and well-being.

6-5. Increase the proportion of adults with disabilities reporting sufficient emotional support.

Target: 79 percent.
Baseline: 71 percent of adults aged 18 years and older with disabilities reported sufficient emotional support in 1998 (data from 11 States and the District of Columbia; age adjusted to the year 2000 standard population).
Target setting method: 11 percent improvement (parity with adults aged 18 years and older without disabilities in 1998).
Data source: Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP.

Adults Aged 18 Years and Older, 1998	Reported Sufficient Emotional Support*	
	With Disabilities	**Without Disabilities****
	Percent	
TOTAL	71	79
Race and ethnicity		
American Indian or Alaska Native	56	72
Asian or Pacific Islander	49	66
Asian	DSU	DSU
Native Hawaiian and other Pacific Islander	DSU	DSU
Black or African American	53	68
White	74	82
Hispanic or Latino	44	68
Not Hispanic or Latino	72	80
Black or African American	DNA	DNA
White	DNA	DNA

Adults Aged 18 Years and Older, 1998	Reported Sufficient Emotional Support*	
	With Disabilities	Without Disabilities**
	Percent	
Gender		
Female	70	79
Male	70	78
Education level (aged 25 years and older)		
Less than high school	58	70
High school graduate	74	76
At least some college	74	83

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.
Note: Age adjusted to the year 2000 standard population.
*Data are from 11 States and the District of Columbia.
**The total represents the target. Data for population groups by race, ethnicity, gender, socioeconomic status, and geographic location are displayed to further characterize the issue.

Emotional support often is derived from a person's social support systems. Two hypotheses suggest that social support helps a person cope with stress and that supportive relationships are a protective factor in various life situations.[26] With the information gained by monitoring the personal perspective, the United States may better meet the needs of people with disabilities.

6-6. Increase the proportion of adults with disabilities reporting satisfaction with life.

Target: 96 percent.
Baseline: 87 percent of adults aged 18 years and older with disabilities reported satisfaction with life in 1998 (data from 11 States and the District of Columbia; age adjusted to the year 2000 standard population).
Target setting method: 10 percent improvement (parity with adults without disabilities in 1998).
Data source: Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP.

Adults Aged 18 Years and Older, 1998	Reported Satisfaction With Life*	
	With Disabilities	Without Disabilities**
	Percent	
TOTAL	87	96
Race and ethnicity		
American Indian or Alaska Native	78	92
Asian or Pacific Islander	78	98
Asian	DSU	DSU
Native Hawaiian and other Pacific Islander	DSU	DSU
Black or African American	83	92
White	88	96
Hispanic or Latino	80	93
Not Hispanic or Latino	87	96
Black or African American	DNA	DNA
White	DNA	DNA
Gender		
Female	87	95
Male	86	96
Education level (aged 25 years and older)		
Less than high school	84	94
High school graduate	87	95
At least some college	89	97

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.
Note: Age adjusted to the year 2000 standard population.
*Data are from 11 States and the District of Columbia.
**The total represents the target. Data for population groups by race, ethnicity, gender, socioeconomic status, and geographic location are displayed to further characterize the issue.

Satisfaction with life is associated with the more general term "quality of life," which is a personal evaluation of one's own position in numerous dimensions of life, including physical, emotional, social, spiritual, environmental support, and level of independence.[27] Monitoring the life satisfaction of people with disabilities, as well as that of the broader population, allows an opportunity to evaluate society's progress in accommodating the needs of people with disabilities.

6-7. Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.

Target and baseline:

Objective	Reduction in People With Disabilities in Congregate Care Facilities	1997 Baseline	2010 Target
		Number of Persons	
6-7a.	Persons aged 22 years and older in 16 or more bed congregate facilities	93,362	46,681
6-7b.	Persons aged 21 years and under in congregate care facilities	24,300	0

Target setting method: 50 percent improvement for 6-7a; total elimination for 6-7b.

Data source: Survey of State Developmental Disabilities Directors, University of Minnesota.

Many people with activity limitations or cognitive impairments need ongoing and long-term assistance, yet some do not require institutional care.[28] From the 1970s through the 1990s, States began reducing the size of and closing State institutions that served people with mental retardation or developmental disabilities. This social, political, and economic movement resulted in a dramatic growth in the total number of individuals served in community residential settings—from 5,000 in 1960 to 255,117 in 1996.[29], [30] This movement, coupled with increases in life expectancy and an expanding elderly population, resulted in the development of several community-based and in-home assistance programs, such as home-delivered meals, hospice care, and homemaker and home-health services. The goal to increase home and community-based care will broaden health and lifestyle choices for people with disabilities and their families.[31]

Much of this expansion in community services is funded through the Medicaid Home and Community-Based Services (HCBS) Waiver Program, a Federal-State partnership authorized in 1981 under Title XIX of the Social Security Act. Between 1990 and 1997, the HCBS Program demonstrated a 25.8 percent increase in benefits per person.[30] Despite this dramatic growth to support home and community-based care, in 1993, only 11 percent of long-term Medicaid expenditures and 5.3 percent of total Medicaid expenditures went toward community-based care.[32] The other sources of support for community-based long-term care are Medicare, Title III of the Older Americans Act, and the Social Services Block Grant.[32]

6-8.   Eliminate disparities in employment rates between working-aged adults with and without disabilities.

Target: 82 percent.

Baseline: 52 percent of adults aged 21 through 64 years with disabilities were employed in 1994–95.

Target setting method: 58 percent improvement (parity with adults without disabilities in 1994–95).

Data source: Survey of Income and Program Participation (SIPP), U.S. department of commerce, bureau of the census.

Adults Aged 21 through 64 Years, 1994–95	Employment of People With Disabilities	Employment of People Without Disabilities*
	Percent	
TOTAL	52	82
Race and ethnicity		
American Indian or Alaska Native	41	77
Asian or Pacific Islander	48	78
Asian	DNC	DNC
Native Hawaiian and other Pacific Islander	DNC	DNC
Black or African American	37	77
White	DNA	DNA
Hispanic or Latino	45	76
Not Hispanic or Latino	DNA	DNA
Black or African American	DNA	DNA
White	57	84
Gender		
Female	46	75
Male	60	90
Education level		
Less than high school	34	69
High school graduate	54	81
At least some college	63	83

DNA = Data have not been analyzed. DNC = Data are not collected. DSU = Data are statistically unreliable.

*The total represents the target. Data for population groups by race, ethnicity, gender, and socioeconomic status are displayed to further characterize the issue.

The ability to work has implications for economic and social self-sufficiency, for full inclusion and integration into society, and for personal self-esteem. Work and disability are understood best within the context of a person's abilities and the role of accommodation, accessibility, and legal mandates. The Presidential Task Force on Employment of Adults with Disabilities emphasized the need for a coordinated and aggressive national policy to address the many components of work and disability.[33] Changes in economic policies and benefits underscore the need to continue to examine and address the structural, social, and psychological deterrents to work for some persons with disabilities.

In 1994–95, employment rates varied depending on degree of disability. For persons aged 21 through 64 years with no disability, the rate was 82 percent, whereas those with a nonsevere disability had a rate of 77 percent, and those with a severe disability had a rate of 26 percent. Analyses of rates by gender indicate similar patterns.[2] Moreover, employment patterns for persons with disabilities mirror general social patterns of employment rates for age, race, and ethnicity.[34] Education has a positive association with employment for all people, although the association is strongest for adolescents and adults with a "work disability."

6-9. Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

Target: 60 percent.
Baseline: 45 percent of children and youth aged 6 to 21 years with disabilities spent at least 80 percent of their time in regular education programs in the 1995–96 school year.
Target setting method: 33 percent improvement. (Better than the best will be used when data are available.)
Data source: Data Analysis System (DANS), U.S. Department of Education, Office of Special Education.

Data for population groups currently are not analyzed.

This objective aims to improve the well-being of students with disabilities by encouraging academic and learning opportunities and nonacademic social and emotional experiences that can facilitate normal growth and development, postsecondary educational attainment, independent living skills, and economic participation as adults. Serving students with disabilities in regular nonspecial education classrooms is a concern that cuts across the goals of many Federal agencies. The current target of the Office of Special Education and Rehabilitative Services is that 60 percent of children and youth with disabilities aged 6 through 21 years will be reported by the States as being served in the regular education classroom at least 80 percent of the time. In

support of the target, the 1997 Amendments to the Individuals with Disabilities Education Act states that "to the maximum extent appropriate, children and youth with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled."[35]

6-10.   (Developmental) Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

Potential data source: National Independent Living Centers Network.

For people with disabilities to have the opportunity for healthy lives, both physically and emotionally, programs and facilities that offer wellness and treatment services must be fully accessible. Effective enforcement of the Americans with Disabilities Act can improve services for people with disabilities and help prevent secondary disabilities.

6-11.   (Developmental) Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.

Potential data source: National Health Interview Survey (NHIS), CDC, NCHS.

In 1990, a one-time survey showed that 2.5 million people said they needed assistive technology that they did not have.[36] The inability to pay for such technology was the main reason given for the unmet need. Assistive technology can be critical in the lives of people with disabilities; thus, technology need, availability, and use must be studied.[37] Technology can aid the independence and self-sufficiency of people with disabilities and can enable people to work, attend school, and participate in community life. Without assistive technology, people with disabilities may become dependent and isolated.

6-12.   (Developmental) Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

Potential data source: Behavioral Risk Factor Surveillance System (BRFSS), CDC, NCCDPHP.

The focus on measuring the environmental impact on people with disabilities echoes the underlying theme of the disability rights movement and the ADA.[38] Both argue that the most important outcome for persons with disabilities—in fact, for all persons in the United States—is

their full participation as active, involved, and productive members of society. Indeed, this participation is the implicit outcome for the overarching Healthy People goals to achieve a healthier life and eliminate disparities.

A special 1999 Colorado Behavioral Risk Factor Surveillance System (BRFSS) survey showed that compared to 43 percent of people without disabilities, 55 percent of adults aged 18 years and older with disabilities reported encountering environmental barriers daily or weekly and/or barriers that were very problematic.[39] Similar data will be collected from several other States.

Full participation cannot be achieved without eliminating environmental barriers found within architectural structures, technology, organizational policies and practices, and social attitudes and without moving toward universal design and nondiscriminatory elements. Thus public health agencies need to measure not only the nature and extent of disability in the United States but also the extent to which environmental barriers and universal design elements impede or facilitate social participation.

6-13. Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

Target and baseline:

Objective	Increase in Public Health Surveillance and Health Promotion Programs for People With Disabilities and Caregivers	1999 Baseline	2010 Target
		Number	
6-13a.	States and the District of Columbia	14	51
6-13b.	Tribes	Developmental	

Target setting method: Total coverage.
Data sources: Tribal, State, and District of Columbia reports; Office on Disability and Health, CDC.

The needs of people with disabilities and caregivers should be addressed by public health activities. In a telephone survey, 23 percent of all U.S. households included at least one caregiver.[40] While not all people with disabilities are dependent on the services of an unpaid (usually a family member) or paid caregiver, meeting the needs of those who benefit from personal assistance cannot be easily separated from the needs of people who provide assistance.[41] Whether caring for infants, children, or adults with disabilities or for the increasing number of people who become activity-limited as they grow older, the caregiver is an important health component.[42]

Related *HP2010* Objectives From Other Focus Areas

1. **Access to Quality Health Services**

    1-1.   Persons with health insurance

    1-4.   Source of ongoing care

    1-5.   Usual primary care provider

    1-6.   Difficulties or delays in obtaining needed health care

    1-16. Pressure ulcers among nursing home residents

2. **Arthritis, Osteoporosis, and Chronic Back Conditions**

    2-3.   Personal care limitations

    2-5.   Employment rate

    2-8.   Arthritis education

    2-11. Activity limitations due to chronic back conditions

3. **Cancer**

    3-9.   Sun exposure and skin cancer

    3-11. Pap tests

    3-12. Colorectal cancer screening

    3-13. Mammograms

4. **Chronic Kidney Disease**

    4-2.   Cardiovascular disease deaths in persons with chronic kidney disease

    4-7.   Kidney failure due to diabetes

5.   Diabetes

    5-1.   Diabetes education

    5-2.   New cases of diabetes

    5-3.   Overall cases of diagnosed diabetes

    5-4.   Diagnosis of diabetes

    5-9.   Foot ulcers

    5-10. Lower extremity amputations

7.   Educational and Community-Based Programs

    7-1.   High school completion

    7-3.   Health-risk behavior information for college and university students

    7-6.   Participation in employer-sponsored health promotion activities

    7-11. Culturally appropriate and linguistically competent community health promotion programs

    7-12. Older adult participation in community health promotion activities

9.   Family Planning

    9-2.   Birth spacing

    9-4.   Contraceptive failure

    9-7.   Adolescent pregnancy

12. Heart Disease and Stroke

    12-1.   Coronary heart disease (CHD) deaths

    12-7.   Stroke deaths

    12-9.   High blood pressure

20. Occupational Safety and Health

    20-1. Work-related injury deaths

21. Oral Health

    21-1.   Dental caries experience

    21-2.   Untreated dental decay

    21-3.   No permanent tooth loss

    21-4.   Complete tooth loss

    21-5.   Periodontal disease

    21-6.   Early detection of oral and pharyngeal cancers

    21-8.   Dental sealants

    21-10. Use of oral health care system

    21-15. Referral for cleft lip or palate

    21-16. Oral and craniofacial State-based surveillance system

22. Physical Activity and Fitness

    22-1. No leisure-time physical activity

    22-2. Moderate physical activity

    22-3. Vigorous physical activity

    22-4. Muscular strength and endurance

    22-5. Flexibility

23. Public Health Infrastructure

24. Respiratory Diseases

27. Tobacco Use

28. Vision and Hearing

Chapter 6 Terminology

(A listing of abbreviations and acronyms used in this publication appears in Appendix H.)

Activity limitations: Problems in a person's performance of everyday functions such as communication, self-care, mobility, learning, and behavior.

Assistive devices and technology: Under the Assistive Technology Act of 1998 (Public Law 105-394), "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities."

Congregate care facilities: An out-of-home facility that provides housing for people with disabilities in which rotating staff members provide care—16 or more beds when referring to adults and any number of beds when referring to children and youth under age 21 years. Congregate care excludes foster care, adoptive homes, residential schools, correctional facilities, and nursing facilities.[30]

Disability: The general term used to represent the interactions between individuals with a health condition and barriers in their environment.

Environmental factors: The policies, systems, social contexts, and physical barriers or facilitators that affect a person's participation in activities, including work, school, leisure, and community events.

Health promotion: Efforts to create healthy lifestyles and a healthy environment to prevent medical and other secondary conditions, such as teaching people how to address their health care needs and increasing opportunities to participate in usual life activities.

ICIDH-2: *International Classification of Functioning and Disability*, the World Health Organization's conceptual and coding framework for describing a person's functioning and disability associated with his or her health condition.

People with disabilities: People identified as having an activity limitation or who use assistance or who perceive themselves as having a disability.

Permanency planning: A planning process undertaken by public and private agencies on behalf of a child with developmental disabilities and their families with the explicit goal of securing a permanent living arrangement that enhances the child's growth and development.[41]

Secondary conditions: Medical, social, emotional, mental, family, or community problems that a person with a primary disabling condition likely experiences.

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SYNTHESIS OF WORKGROUP REPORTS

Healthy People 2010, the health agenda for the United States for this decade, asserts goals to improve the quantity and quality of life for all Americans and eliminate disparities in health across diverse segments of the population. The 476 objectives defined in *HP 2010* encompass most aspects of our lives as citizens—from birth to death, across social, economic, ethnic and racial lines to include, for the first time, people with disabilities. By adding "people with disabilities" as one of the ways in which people in our country can be described, the health of people who experience disabilities can be viewed alongside the health of people without disabilities. This action creates an opportunity for public health to focus specific attention on people experiencing disabilities, thus moving this large minority group into the mainstream of public health.

As part of this public health agenda, a separate chapter with 13 objectives, *Disability and Secondary Conditions*, was included in *HP 2010*. (The Chapter 6 document of *HP 2010* is included in this volume, see page 7.) In addition to establishing disability status as one of the descriptor variables for more than 100 objectives, Chapter 6 focuses on pertinent issues of health and well-being for people with disabilities. The 13 objectives, each representing important aspects of our lives, were hammered out over 4 years by numerous individuals and organizations, and represent all sectors of the disability community.

In order to obtain direction in achieving each of these objectives, 80 people were invited to Atlanta in December 2000 to divide into 13 workgroups. The groups were asked to respond to five implementation questions. The participants of these workgroups (see Appendices) represented disability leadership as varied as is the population of people with disabilities. This paper is a synthesis of reports from those workgroups and is divided by the topics addressed in each of the five implementation questions. In addition, seven crosscutting themes identified throughout the 13 objectives provide perspective for analyzing the information from the workgroup reports. These themes will be used to highlight differences within some of the questions.

The 80 participants were asked to address the following five implementation questions.
1. How *practical* are the targeted objectives for implementation by the year 2010?
2. What are the major *problems* in addressing this objective?
3. Who are the governmental, non-governmental private and other Healthy People Consortium members who could/should be *partners* in implementing this objective?
4. What are initial *programs,* current or envisioned, and/or *policies* that could help meet this objective?
5. Are adequate mechanisms in place for tracking *progress* toward meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

Themes emerging from the objectives include the following:

- Data
- Children/school
- Social/emotional health
- Participation/work
- Environment/accessibility
- Caregivers/long-term care
- State activities

1. How *practical* are the targeted objectives for implementation by the year 2010?

This discussion begins the journey. Because *HP 2010* marks the first time that specific disability objectives have been included in *Healthy People*, one would expect questions about how reasonable objectives are, how feasible the targets are, and whether the resources needed to achieve particular objectives are within reach. Most workgroups indicated that while the objectives were both reasonable and possible to implement by the end of the decade, a pervasive concern was the need for resources, both human and financial, if the objectives were to be implemented. Several groups focused on the definitions used in the objectives. Specific issues emerged from the deliberations.

DATA

The core principle of the Healthy People exercise is that health issues can be translated into numbers (representing baselines) to set targets that measure progress toward better health. The first objective in Chapter 6 emphasizes the need for questions to identify people with disabilities so that their health characteristics can be compared with the rest of the population, and thus can we assess health disparities. For this objective to occur, a small set of questions must be included in any health-related survey. The workgroup for Objective 6.1 indicates that while the current items used in surveillance tools differ, they are acceptable for the time being. Participants were clear, however, that more congruence in operational definitions is needed at both the federal and state levels. Workgroup members suggested that the revision of the World Health Organization's conceptual framework of functioning, disability, and health be used as the standard for understanding data elements. When possible, specific dimensions of the *International Classification of Functioning, Disability, and Health (ICF)* should be used to develop items for instruments.

Finally, participants in the children's mental health objective (6.2) workgroup expressed the concern that public health population-based data be used rather than clinically oriented data. By contrast, the adult mental health workgroup (Objective 6.3) suggested that more clinical data be employed to assess the practicality of implementing interventions.

SOCIAL/EMOTIONAL HEALTH

Evaluating the practicality of the emotional support/mental health objectives is a delicate matter. The workgroups suggest that achieving parity is a difficult target in the mental health area, given the environmental barriers facing people with disabilities—including societal attitudes, media presentation, and lack of resources.

PARTICIPATION/WORK

On the other hand, according to the way definitions are framed, the employment goal may be too easy to reach. That is, when the statistics are averaged across various severity levels of disability, the difficulty experienced by individuals with more involved conditions is disguised.

ENVIRONMENT/ACCESSIBILITY
All three of the developmental objectives pertain to the general area of environment and accessibility. By definition, then, there are no current data, making the practicality a moot point—on the surface. However, if this area were not crucial to the health of people with disabilities, these objectives would not have been framed, much less accepted into the final *HP 2010* document. It is reasonable to include them, and the need for data is pivotal. The *ICF* framework that describes the environment is useful for structuring this investigation.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch have concluded an agreement by which data to measure this objective will be included in the NHIS supplement during 2002.

Once the baseline data are analyzed, appropriate targets can be set. Of particular interest to this area is the practicality of injecting into the society the principles of universal design. While there is not a specific objective naming universal design, the workgroup asserted the importance of implementing these principles.

STATE ACTIVITIES
Beyond resources, the major element of practicality within this area focused on the lack of activities related to caregiving data and programs in states. It is clear that addressing caregiving is a practical part of the objective, but the workgroup suggests that it be seen as developmental in nature.

2. What are the major *problems* in addressing this objective?

An overarching theme of the workgroup responses is the lack of coalitions and champions, Congressional or otherwise, for disability and health issues.   The lack of coordinated leadership and a widespread misunderstanding of disability in the general population are significant problems across disability issues, including health. Specifically, disability is often perceived by the general population to be a negative health outcome rather than a demographic or descriptive variable.

A major problem for meeting health objectives occurs when the experience of disability is devalued. Media messages often reflect notions that contribute to poor self-concept and low self-esteem.   A lack of education for people with disabilities and parents of children with disabilities undermines the potential antidote for such messages. A troublesome corollary to the negative attitudes of the population is the lack of attention to additional environmental barriers. In particular, no organization or agency is responsible for assessing barriers or eliminating them once they are identified.

Other major problems raised by the workgroups can be divided into several categories:

Technical problems. There are technical problems, including inconsistent definitions of terms such as full access, environmental barrier, and disability itself. In certain areas there is a lack of psychometrically sound measures for assessing objectives. There is often a lack of visibility for certain subgroups of people with disabilities, including individuals in institutions, those who are deaf, and children.

Resource problems. Resource allocation problems identified by the workgroups included fragmentation of funding streams for programs. There are disparities across states in commitments of resources, energy, and leadership.   In addition, there are no incentives for the private sector, including employers, to be involved in promoting the health of people with disabilities. Parity in reimbursement for mental and physical conditions has been and often continues to be problematic. Inconsistent insurance coverage also undermines preventive and other health services.

Service integration problems. In schools, the lack of service integration is a major barrier. Parents are required to be case managers, which often creates additional physical and emotional problems for the parents. Mental health needs of people with disabilities, and children in particular, are often ignored or underidentified.

Training problems. Finally, the workgroups routinely indicated that health professionals need training in disability issues. Poor understanding of the dynamics of the disabling process, the role of environmental barriers, and the diagnosis-centered versus person-centered approach are identified as specific deterrents to meeting the objectives.

3. Who are the governmental, non-governmental, private, and other Healthy People 2010 Consortium members who could/should be *partners* in implementing this objective?

The workgroups are unanimous that the only way to achieve the objectives of the disability and secondary conditions chapter is to build effective coalitions. Coalitions require groups and individuals to lay aside less important missions for more important ones. The partners identified by all workgroups ran the spectrum from local to national, and often international, organizations. They included large and small, general and specific, formal and informal, health care and health-related organizations. While all sectors of the disability community should be included, several groups reported the need to foster cooperation and collaboration among organizations not usually linked to the disability community, for example, architects and city planners.

Frankly, it is easy to get so involved in identifying potential partners that we overlook the fact that identification is but the first step in building partnerships. However, without knowing who could be helpful, we may tend to hold too tightly to our own perspective. No one approach will achieve an objective. Multiple interventions across different sectors attending to different features of the objective will be required. Identifying partners allows us to begin to communicate, then cooperate, and then collaborate on objectives held in common. If

partnerships are seen as concentric circles, several levels could be identified working from the person toward societal partners. Almost without exception, the workgroups identified progressively more extensive layers of partners.

LAYERS OF PARTNERS

**Level One**: Most begin with people with disabilities and their families. This group includes parents of children with disabilities and grown children of parents with disabilities—both caregivers.

> _**Level Two:**_ Community organizations, clubs, and faith-based groups are the second level of partnerships needed for some objectives. This group includes Centers for Independent Living, as well as support groups that may be diagnosis-specific or more general in perspective. This second level also includes medical and health care providers.

>> _**Level Three:**_ A third level of partners includes employers, corporations, and industry. Labor unions will be included as partners for some objectives. State-based local agencies such as Vocational Rehabilitation, Developmental Disability Councils, and Special Education as well as designers, builders, and planners are also included in this level of partners.

>>> _**Level Four:**_ This level is that amalgam of organizations that look at the "big picture." There are many of them, but for our purposes they can be identified as advocacy groups, professional organizations and training programs, health care financing and accreditation organizations, federal and state agencies, foundations, and the media.

4. What are initial _programs_, current or envisioned, and/or _policies_ that could help meet this objective?

The workgroups' responses to this question highlight the breadth, depth, and creativity needed to achieve the objectives. The answers to the questions on practicality (#1) and problems (#2) may evoke an image of the Greek mythical character Sisyphus trying to roll a boulder up a mountain. The responses to this fourth question, however, coupled with the partnerships (#3), provide guidance about whom to enlist to help push the boulder (partners) and instructions about how to break the boulder into smaller, more easily moved rocks or even pebbles (policies and programs). The information will be presented here by theme, but also according to the current or proposed nature of the activity. The reader will find that continuous emphasis is placed on training of professionals, financial incentives, and local and federal programs, along with major emphasis on media management.

DATA
Promoting "disability status" as a demographic variable is a policy that has already begun, but needs continued emphasis. While research is currently being done to clarify operational definitions for both children and adults with disabilities, two related activities are needed immediately. First, ensure that those survey instruments that include disability identifiers are tracking the appropriate objectives in other chapters (see Chapter 6: related objectives). Second, identify those instruments that do not include disability items and begin the process of persuasion—perhaps different for each instrument and/or related objective— that will be needed

to have disability status included. Of particular importance are those objectives identified by the Surgeon General's office as "Leading Health Indicators" (included in this report as Appendix I, see page 169).

Longer-term directions include promoting a framework for understanding disability data across surveys, the leading contender being the WHO *International Classification of Functioning, Disability, and Health*. A toolkit of optimal disability measures should be developed. Examples are the instruments developed by Drs. Gale Whiteneck, David Gray, and Rune Simeonsson to measure participation and environmental factors for adults and children. Finally, there must be continual efforts to find ways to include undercounted groups in the disability community; for example, young adults with cognitive impairments are often lost to surveys after they reach young adulthood.

CHILDREN/SCHOOL
The workgroups addressing children's mental health and school inclusion provide complementary directions. The first programs and policies focus on extension of current programs. These include extending Early Intervention programs to transition times for children—beginning and leaving school and entering adolescence. Expanding the Early Periodic Screening and Developmental Testing program as a foundation for physical and mental health was also recommended. Continued emphasis on gaining parity for the coverage and financing of physical and mental health services was recommended. Increased training for professionals in schools, mental health and public health activities, and other health care and school specialists was strongly endorsed. Particular attention should be paid to training educational staff regarding inclusion principles and practices. In addition to school inclusion, social inclusion through community programs, clubs, camps, and faith-based groups needs to grow. These programs parallel the overall emphasis on teaching and allowing children self-determination. Personal assistance services at school would reinforce emphasis on individual autonomy and should be explored more fully. Technology should be enhanced on behalf of physical and mental health through use of telemedicine/telehealth models. Also, universal design needs to be encouraged in schools and communities along with access to technology that can accommodate children's different functional skills and styles. Finally, family support programs across these settings must be strengthened.

The programs are founded on the principle that the health and well-being of children and their families is a shared responsibility. Politics aside, the United States is one of but two countries yet to ratify the United Nations Convention on the Rights of the Child. Achieving our goals for children will rest upon adherence to those rights, and having our nation officially affirm them will provide evidence of our commitment to all our children.

SOCIAL/EMOTIONAL HEALTH
The workgroups focusing on emotional support and health of adults with disabilities emphasized the need for interventions from individual to community to national in scope. Beginning with strong clinical interventions, including peer programs such as the one at the University of Houston, and community-based programs such as *Living Well with a Disability*, broad strategies should be enhanced. Social connections such as those often available through Centers for Independent Living or community recreation centers and churches will allow progress to be

made toward achieving these goals. Incentives to encourage employment can enhance mental health and social and emotional support.

The workgroups also emphasized the systemic supports needed to achieve these objectives. Beginning with the media, education and training of professionals is needed. Efforts to help the media understand and change their often unwitting, but nonetheless negative, representations of disability are imperative. In addition, programs to improve transportation, transfer technology, and implement universal design contribute to improved mental health status through increased accessibility. Life satisfaction is heightened.

Finally, financial incentives at several levels would be helpful. Reimbursement parity between physical and mental health services is again recommended. Financial incentives to encourage participation were suggested. Tax credits and medical-expenditure arrangements were also incorporated into the workgroup reports. It is sufficient here to communicate the breadth of possible directions to influence these objectives positively, even in the face of major obstacles.

CONGREGATE/LONG-TERM CARE

This workgroup developed parallel emphases from the one objective, Objective 6.7. The report suggests that as congregate care for children and adults with disabilities is decreased, other issues will emerge. The principles of permanency-planning for children with disabilities, and person-directed planning for adults with disabilities, must be expanded. The report indicates that states such as Texas and Michigan have developed prototypes for implementing these principles. Substantial planning efforts are needed so that appropriate supports are in place for successful integration in the community through family-based programs. Financial resources need to be associated with a person, not a program or bed. Incentives for family and community living, rather than institutional living, should be both policy and practice. As progress is made toward this objective, the concept of "aging in place" can be encouraged. Community services should be a *sine qua non*—a given—in order that the objective be met effectively. Simply moving people out of congregate care without requisite supports would be a hollow and immoral conclusion to a worthy goal.

Finally, the recurring theme is sounded for training providers working in congregate care as well as the community. The basic lack of understanding of disability-related issues combined with a general disrespect for the experience of disability often create workers unable to respond humanely to individuals who need to have choices and make decisions about their lives to the fullest extent possible.

WORK/PARTICIPATION

The reports from the two workgroups (Objectives 6.4 and 6.8) have in common involvement in societal activities. Specific directions that need expansion include increased access to transportation and assistive technology, without which full participation is undermined. Employer and public accommodations compliance with the Americans with Disabilities Act (ADA) is also included as a foundation for achieving these objectives.

To achieve the employment objective, it is recommended that the vocational rehabilitation model be overhauled and services follow the updated model. Eliminating disincentives to work, while providing incentives (e.g. small businesses) will be needed.

A final incentive to increasing work and societal participation will be including maintenance as part of reimbursable payments in addition to restorative therapies.

ACCESSIBILITY/ENVIRONMENT
There are few already existing policies and programs for the objectives focusing on accessibility and environmental barriers. The first important direction to achieve these objectives is a coherent policy that integrates the varied levels of activity required to open the society for full access. Developing measures of accessibility is a crucial step, without which progress cannot be measured. The conceptual background is provided, but the practical development of tools is just beginning.

Establishing standards, guidelines and policies to establish a code of inclusion and accessibility is a primary effort. Expanding funding for health and wellness programs would encourage people with disabilities to be more health focused, and health and wellness programs to be more aware of this population. In addition, providing tax incentives for facilities to be ADA-compliant should be considered. Creative use of specific state sources, such as the tobacco industry settlement funds, could include in this agenda the health of people with disabilities. Certification could also provide incentives for facilities to be accessible to people with disabilities.

This is but a glimpse of the policies and programs included in the workgroup reports. Without the sincere and extended efforts of partners, with shared commitment and clear activities around which to coalesce, the magnitude of the work is overwhelming.

STATE AND LOCAL ACTIVITIES
To some degree, the activities included in the section of congregate and long-term care, participation, and environmental barriers are closely aligned with those of this objective. Directions that will affect people with disabilities are intertwined with issues of independence, health maintenance, and self-determination. Programs at the state and local level directly contribute to or undermine these goals.

As with all areas, data are critical elements. It has been very difficult to tailor questions that will identify people with disabilities. The questions to identify caregiving are easier to construct, but little public health emphasis has been given to including them in surveys. Data are needed to characterize people with disabilities as well as caregivers.

As more states and communities are exposed to disability issues, there will be an increased need for assistance to develop relevant programs. This may come in the form of specific activities addressing only people with disabilities. It may more frequently be part of a larger community or state program addressing a specific public health concern. For example, most everyone can profit from more physical activity and better nutrition. People with disabilities are more

vulnerable to difficulties in these areas, however, and state and local activities should be targeted to people with disabilities.

Disability-awareness activities are important for the general public, and the Media will be important partners. Materials need to be developed to encourage people with disabilities to be more assertive in directing their own health. Community-based interventions are an integral part of achieving the objective.

Educating and training public health professionals is another important direction if public health is to integrate people with disabilities into its national agenda. Financing of health services will also be integral to including people with disabilities in state and local activities. Particular emphasis should be given to evaluating the cost-effectiveness of interventions that prevent secondary conditions and promote the health of people with disabilities.

5. Are adequate mechanisms in place for tracking *progress* toward meeting the targeted objectives? If not, what need to be done to institute such tracking mechanisms?

Overall, workgroups indicated that most data sets that are currently in place to track objectives are adequate. It would be fair to say that no workgroup was extremely satisfied at the time the meeting was convened. Several workgroups were very concerned about the database for their objectives. These concerns are reflected in the reports, but additional new information is always placed in the reports. Two very positive steps have occurred since the completion of the workgroup meeting in December 2000.

First, an agreement between CDC's National Center for Health Statistics and CDC's Disability and Health Branch (within the National Center on Birth Defects and Developmental Disabilities) will allow *Disability and Secondary Conditions* questions to be included in the National Health Interview Survey (NHIS) supplements in 2001 and 2002. Questions in 2001 will address Objectives 6.4, 6.5, and 6.6. This will provide items that will more clearly assess participation (6.4) while providing national population-based data for Objectives 6.5 and 6.6. These latter two objectives had used data from 14 states as the initial baseline. In 2002, questions addressing the three developmental objectives (6.10, 6.11, and 6.12) will be included, thereby providing baseline data for these objectives. Targets for all the objectives can be set.

Second, the Leading Health Indicators (LHIs) have been selected by the Department of Health and Human Services (DHHS) (see Appendix I in this report). These 10 indicators include 22 objectives from *Healthy People 2010,* and will provide an annual progress report for the nation. It is a Chapter 6 goal that people with disabilities be included early in these reports. Sinclair and Campbell have recently completed an analysis of data from the Behavioral Risk Factor Surveillance System (BRFSS) that addresses all 10 LHIs. While the official Healthy People data sets do not cover all LHIs for people with disabilities, this is a firm foundation from which to proceed.

Several other tracking issues were raised by workgroups. There was a trend to encourage the linkage of data sets to evaluate progress toward certain objectives. Several workgroups were

concerned that certain subgroups were not as clearly identified. School inclusion needs to be monitored by special education classifications, not just globally. Given the significant disparities for Native Americans, tribes need to be included in the target for public health and disability state programs. Several objectives indicated that disability should be differentially tracked by specific activity limitation, such as mobility, communication, learning, or behavior.

SUMMARY
Each workgroup focused intensely on one of the 13 objectives in the *Disability and Secondary Conditions,* Chapter 6, of the *Healthy People 2010* agenda. They worked to balance the need for scientific public health rigor with the passion for social justice for people with disabilities. They recognized that disability is a fledgling area in the well-established public health field. The workgroups acknowledged that we will learn a lot over the next few years as we begin our work to achieve these objectives, thereby making some of the problems, programs and policies dated. Their clearest message, however, is that partners—enduring and committed partners—are essential for achieving the objectives and the broader mission of improving the health of people with disabilities during this decade.

PROCEEDINGS

OPENING COMMENTS
Healthy People 2010 Symposium
D. J. Lollar, Ed.D.
National Center on Birth Defects and Development Disabilities
Centers for Disease Control and Prevention
Atlanta, Georgia
December 4-5, 2000

Thank you for coming–knowing holidays are near, and much work is upon you all. I must also thank Lisa Sinclair for co-leading the chapter and this meeting, as well as Larry Burt, Gloria Dixon and Jennifer Nun for facilitating this meeting. And a thank you goes to Jim Morrill, with Courtesy Associates, who produced this meeting. Finally, I want to thank Ray Seltser, without whom the substance of the background material would be substantially weaker. His commitment to *Healthy People* through the years has kept disability issues before government officials when they didn't want to look at them.

The *Healthy People* project is an ambitious activity. From humble beginnings over 20 years ago, it has survived and flourished across four government administrations so far, with bipartisan support. The 467 objectives in the 28 chapters of *Healthy People 2010* represent the work of thousands of people both within and outside government.

This is the first time that people with disabilities have been given a substantial place in the agenda. This effort began almost 4 years ago and has included more than 150 individuals from 75 organizations generating close to 200 potential objectives. These final objectives in Chapter 6 represent the best combination of disability needs and data viability.

The objectives look to be worthy of effort. They suggest that the purview of public health has expanded to include what the World Health Organization has called "a state of complete well-being—physical, social and mental, and not merely the absence of disease." This implies that there is a mandate to address factors that fall outside the usual understanding of "health," such as housing, transportation, education, and adequate resources for living. You see in these objectives issues of children and adults, people with disabilities and caregivers, physical and mental health, environmental factors, assistive technology, education, workplace issues, state public health programs, and the issue of data.

The objectives may seem inclusive, while a look at the measures for each objective may seem restrictive. Taking an objective and translating it into information that can be collected across the population of the United States is a daunting task. We have been, and will continue to be, working on the data issues. Be aware of them, but don't let them hamper your focus on programs, policies, and practices that will move us toward the stated objective. As momentum grows, we will strengthen the data.

You are here because you are people who see beyond your own situation to the larger picture. Included among you are 20 university people, 23 government employees, and representatives

from 37 nongovernmental organizations (NGOs). The disability community is growing rapidly. You may not know some others in your workgroup. Know that you each represent a part of that community with both an individual and group perspective. Addressing these objectives will require a broad view, while using the knowledge learned from your local activities is required to inform the broader world.

Your breadth or depth of discussion may cross into other objectives, within or outside Chapter 6. If it appears that common policies, practices, partners or programs can help more than one objective, terrific. That should emerge when you meet in clusters tomorrow morning.

Be creative and inclusive. Assess how we may involve the private sector as partners. Those companies who profit from the disability community should be allowed to have a part in helping finance health-promotion activities for people with disabilities in the coming decade.

Your task is to answer the questions included in the packet you received for the workgroup/objective you're working on. Each group has an instigator/note-taker with the assumption that I know that none of you are shy. So, instigation is the task of getting folks to introduce themselves, and taking notes—answering the questions—to be given to the project editor, Andrea Sattinger.

The product of these groups will be to provide a framework, and even specifics, by which others will be able to steer a course toward achieving the objectives. We plan a larger conference in early 2002 to marshal forces and resources to flesh out the framework you'll develop here.

If the ADA was the Bill of Rights for people with disabilities, *Healthy People 2010*, Chapter 6, can be the Constitution for Health. Your efforts will provide the foundation for improving the health and well-being of people with disabilities during the next decade. More than that, however, if the objectives are seriously addressed during the coming decade, the efforts will change the face of America. I don't mean to say that this will do it all, for other government and nongovernmental efforts have been, are, and will be working for similar goals. *Healthy People*, however, allows that balance of lofty goals with clear measures so that we can keep our eye on the goals.

The Institute of Medicine report entitled *The Future of Public Health* said on its first page: "Public health is what we as a society do collectively to assure the conditions in which people can be healthy." *Healthy People* and your admittedly hard work will give us a blueprint to make that assurance real.

Again, thanks for being here.

CHAPTER 6 WORKGROUP REPORTS

Objective 6.1: Include in the core of all relevant *Healthy People 2010* surveillance instruments a standardized set of questions that identify "people with disabilities"

Objective 6.1 provides the cornerstone of the *Healthy People 2010 (HP 2010)* objectives for disability. We support the importance and feasibility of the two goals of this objective: (I.) To track consistent data regarding people with disability, and (II.) To compare data on all relevant *HP 2010* objectives between people with and without disabilities.

Assumptions
1. Disability is a demographic descriptor rather than a health outcome.[*] As a descriptor, disability should be used to monitor disparities in health outcomes and social participation. The Americans with Disabilities Act (ADA) provides an important rationale for universal collection of data on disability status.
2. The goals of *Healthy People 2010* are well served by calculating Years of Health Lost (YHL) for people with and without disabilities, and not by such conceptually and operationally flawed indicators as Disability-Adjusted Life-Years (DALYs) or its counterparts, in which disability is presumed to reflect a negative health status.
3. The *International Classification of Functioning, Disability, and Health (ICF)* provides a promising framework for long-term data needs.
4. One of the two overarching goals of *Healthy People 2010* is to eliminate health disparities. Disparities exist for people with disabilities. This goal reinforces the call for ongoing monitoring for the disability status in all relevant surveillance instruments.

I. How *practical* are the targeted objectives for implementation by the year 2010?
We believe that an existing pair of measures[**] is adequate for surveillance use as a first step. However, we recommend setting into motion an agenda for developing a larger disability-surveillance toolkit that would contribute to improving data about both the health status of, and, more generally, related data about people with disabilities.

The feasibility and importance of Objective 6.1 notwithstanding, substantial scientific, dissemination, and implementation issues encountered in trying to meet the objective require action over the course of the decade. Substantial staff and other resources should be dedicated specifically to this objective in order to provide the technical assistance necessary to support this work.

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[*] In order to monitor the health and participation of people with disabilities, and to distinguish people with disability as a select segment of the population to be targeted for health promotion, we support the promotion of disability as a demographic descriptor as opposed to a health outcome.
[**] Following are the two existing questions (currently used in the *National Health Interview Survey [NCHS –NHIS]* and the *National Health and Nutrition Examination Survey [NHANES],* and beginning in 2001, the *Behavioral Risk Factor Surveillance System [BRFSS]):*
  1. Are you limited in any way in any activities because of physical, mental, or emotional problems? *(Yes, No, Don't know/not sure, refused)* (LIMITED)
  2. Do you have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone? (*Yes, No, Don't know/not sure, refused*) (EQUIPMENT)

II. What are the major *problems* in addressing this objective?

A. In both the general public and in the public health community there is widespread misunderstanding of issues pertaining to disability. Established groups and institutions with special interests will continue to apply pressure to use and promote scientific measures and models in health, medicine, and public health agencies which conflict or compete with the disability-related goals of *Healthy People 2010*. These parties view disability as a negative health outcome and people with disabilities are perceived as being outside the purview of traditional public health practice. The two efforts must be equally valued and coexist along the continuum of the lifespan.

B. There is a great need to include people with disability as a "select" population in existing and future surveillance methods and a need to endorse programs and partners that do so.

C. The heterogeneity of people with disability will require educating the public health community about the demographic characteristics associated with the disability variable. This is of crucial importance. Disability is not a static phenomenon, but rather its nature is dynamic; disability varies by context, time, developmental phase, and disability type. Some disabilities may be permanent, stable, and may affect a wide range of physical, behavioral and mental skills; others may fluctuate, deteriorate after flare-ups, or affect only selective skills at a given point in time. For instance, a person in a wheelchair is 'disabled' in an environment that requires mobility that cannot be accomplished in a wheelchair; however, in a wheelchair-accessible environment, that person is not 'disabled.' Another example is a child with arthritis who may be extremely impaired in her mobility in the morning and hardly able to get out of bed. Later in the morning, after medications have begun to work, the same child may jump down the stairs, play with others, and function without limits.

D. In many surveys, substantial groups of people with disability are less visible, not sampled, or in other ways undercounted. This is especially true of those surveys currently under consideration (e.g., BRFSS). One particular concern are the children, persons in congregate care settings, persons who are deaf, and those who are homeless, and those with cognitive disabilities, among others, who are not included and/or are underrepresented.

E. Due to the biased assumptions underlying the construct of and lack of empirical data for Disability-Adjusted Life-Years and their discordance with ADA principles, we reject the use of "DALYs" for tracking *HP 2010* objectives. The use of DALYs undermines this objective—that is, DALYs conceive disability as a negative health outcome rather than a descriptive demographic variable.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective? We recommend following these general activities as they relate to partners. *(Recommendations concerning specific partnerships follow in section IV.)* The status of activities is identified according to whether they will need to assume an ongoing, short-term, or long-term status in surveillance programs. "Ongoing" refers to activities that should be conducted throughout the decade. "Short term" signifies that they should be achieved by mid-course reviews in 2004; where applicable, more definitive dates are suggested in this list. "Long term" signifies activities that should be achieved by 2010.

Foster cooperation and collaboration with other programs that previously have not linked or cooperated with the disability community and their objectives. The traditional public health government organizations have viewed the population with disability as the responsibility of other agencies, i.e., service agencies. Efforts are needed to persuade public health agencies that people with disability are a subset of the population and that the health of people with disability is a public health concern. This activity will require identifying incentives, awards, public relations programs and strategies, and advocates. Examples of this include programs for specific chronic conditions that depend on traditional medical models, but that also can be linked to disability (e.g., diabetes); and medical education and various types of health promotion programs. Traditional medical models need to make way for dynamic biopsychosocial frameworks of disability. The disability community must be brought into this activity. As part of this collaboration, concentrated efforts are needed for risk assessment and intervention research, and a surveillance agenda for people with disability. (Short- and long-term activity).

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective? The following proposed activities are listed in priority order with highest priorities first.

A. Apply a common framework across targeted surveys for understanding disability statistics. Develop mechanisms that will provide acceptable and consistent disability-identification criteria. Provide a comprehensive list of measures that can be researched in a "cross-walking" activity. Surveys and other sources that are specified as data sources for disability-specific (Chapter 6) and referenced (i.e., to other *HP 2010* chapters) objectives need to be identified and examined to determine their ability to differentiate between people with and without disability. If these data sources do include a mechanism to identify people with disability, algorithms need to be created to ensure that common identification attributes are established between the various data sources ("cross-walking"). *Partners for this activity include the Department of Education's (DOE) National Institute of Disability and Rehabilitation Research (NIDRR), the World Health Organization (WHO), etc.* (Short-term and ongoing activity).

B. For those surveys that currently include disability-related questions:
1. **Review and prioritize the other *HP 2010* objectives to identify those with the highest yield and highest priority for data collection.** One problem associated with this activity is that the developmental objectives will be dropped if there are not sufficient data to support them. *Partners for this activity would be those listed in HP 2010 as lead agencies on other objectives that specifically identify people with disabilities.* (Short-term activity).

2. **Work specifically for data issues on Chapter 6 developmental objectives.** This is designated as a very short-term activity; other components of *HP 2010* may include more urgent objectives. (Short-term activity) (See March 2001 status update boxes in Objectives 6.10, 6.11, and 6.12).

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3. **Research and construct a toolkit of optimal disability measures.** Develop new measures and address measurement issues such as validation. While the consistent questions proposed at the beginning of this paper will begin the process, this activity is intended to produce measures that are more completely based on the *ICF*. ***Partners for this activity include the Bureau of Labor Statistics (BLS), WHO, the Centers for Disease Control and Prevention (CDC), the University of Maryland Joint Program in Statistical Methodology, Centers for Excellence in Survey Methodology (University of Maryland, University of Michigan, and others), University of California at San Francisco.*** (Long-term activity).

C. For those surveys without disability-related questions:

1. **Immediately identify opportunities to begin tracking people with disability in major surveys.** Identify opportunities by creating an inventory of surveys and processes for target data collection (the timeframe for this activity is both immediate and ongoing). This requires identifying health objectives not only in Chapter 6, but also in other *HP 2010* chapters that relate to people with disabilities. This activity first requires determining whether the data source for the objective is capable of identifying people with disability as a segment of the population, and, if so, seeking opportunities to apply the consistent questions. Related tasks include enumerating the instruments by disability-related objective, contacting the parties responsible for achieving the health objective, and taking whatever steps are needed to add the disability identification questions to these instruments. The time frame for this is short because of the need to identify at least one data point prior to mid-course review for each developmental activity.

2. **Review and triage the published "leading health indicators (LHI)" package for *HP 2010* and identify areas where the disability community is overlooked.** Disability needs to be promoted as a demographic component for data reports and indicators, especially as it applies to disparities. Examine LHIs for people with disabilities in various surveys (e.g., BRFSS). ***Partners for this effort should be the lead agencies of these indicators.*** (Short-term activity).

3. **"Cross-walk" current tracking research.** This would involve developing recodes for variables that will assist in interpretation among surveys. Undertake an interpretation of the primary measures and other disability definitions must be undertaken. One possible framework for recoding the variables is the *International Classification of Functioning and Disability (ICF)*. There have been efforts using international data sets to recode disability variables from diverse data-collections systems into the *ICF* framework. (Short-term activity, to be completed by the end of 2002).

4. **Promote research on the methods of estimating the type of disability, prevalence, and health status of people with disability in undercounted groups (e.g., those with sensory impairment, in congregate care facilities, children, ethnic groups, and the homeless).** Current and ongoing methods—for example, mental retardation/developmental disabilities (MR/DD), Individuals with Disabilities Education Act (IDEA), and 504, are segmented. (Short and ongoing activity)**.**

D. General education and promotion of disability as a demographic variable
  1. **Articulate and promote the issue of the value of viewing and defining disability as a demographic variable.** This activity involves:
       a. Promoting the understanding of disability as a demographic descriptor with heterogeneity, similar to other grouped classifications such as ethnicity/race or sex.
       b. Promoting, among other programs and public health entities (e.g., state health departments), the concept of identifying people with disability as a select population for *HP 2010* objectives, related to the goal of reducing health disparities. This activity will require support through an identified or developed educational process. (Long-term activity). ***Partners for these two activities include NIDRR and the general public health community, not only as partners but also as a focus for the activity's attention. Targets for this activity include the Association of State and Territorial Health Officers (ASTHO), Council of State and Territorial Epidemiologists (CSTE), and state BRFSS and child survey coordinators.*** (Short-term activity).
       c. Enlisting and informing Congress on disability-related issues, including the need for data, and their overall relevance in health and human rights policies. ***Partners for this activity include non-profit private agencies and disability advocacy groups. This activity includes educating and working with the Office on Management and Budget (OMB).*** (Short-term and ongoing activity).

  2. **Promote media and scientific dissemination of health statistics about people with disability to publications that include the Morbidity and Mortality Weekly Report (MMWR) and other scientific and lay media, particularly those having a broad public-health audience. *Partners for this activity include the Center for An Accessible Society and the media.*** (Short- and long-term activity).

E. Resources
Support Objective 6.1 with specific staff members who will have dedicated time for activities related to this agenda. These activities will require public and private partners to conduct and monitor the progress of Objective 6.1. For this reason, we request the ongoing supervision of progress with Objective 6.1. ***Partners: The lead agency on this list of partners would be CDC. Additional partners might be NIDRR (Disability Statistics Rehabilitation Research and Training Center at UCSF) and academic research groups.*** (Ongoing activity**).**

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

Tracking progress for this objective will be straightforward. Such a heterogeneous population requires a battery of flexible assessment tools. Generic tools will be relatively meaningless in tracking progress since they may be insensitive to the specific needs of a particular population in question. While several *HP2010* tracking instruments contain items that identify a few diagnostic conditions, at this time, only two (2) surveillance tools are standardized to identify people with disabilities: 1) BRFSS, and 2) NHIS. Across the decade, however, this number should increase, reaching all relevant data sets by 2010.

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Objective 6.2: Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed

Introduction
A broad range of societal, familial, and individual factors influences the emotional health and well-being of children who have disabilities and chronic conditions. This objective allows us to capture, in a single outcome measure, the effects of interventions that cross levels of those influences upon these children and their families.

There is universal, international support for this objective, as articulated in the report of the 1989 United Nations' Convention on the Rights of the Child,[1] which asserts that policies and services responding to the needs of all children are a fundamental societal responsibility. The Surgeon General's current initiative concerning children's mental health provides a positive context and leadership for efforts related to this objective.

I. How *practical* are the targeted objectives for implementation by the year 2010?
The targeted goal of reducing a baseline of 31% to a target of 17%[*] is practical for implementation by the year 2010. This conclusion was based on the following points.

A. The Surgeon General's initiative, including a recent conference and report on child mental health,[2,3] provides a context for Objective 6.2. This initiative brings the visibility and credibility of the Surgeon General's office to bear on the underlying issue.

B. The specific target of 17% is derived from the best available assessment related to addressing child mental health. Although another target may ultimately prove more appropriate or feasible (given the variety of factors that affect the psychological well-being of children with disabilities), the NHIS data that are currently available suggest a need to focus on overcoming the disparity between children with and without disabilities. (See Objective 6.1 regarding disability as a demographic descriptor.)

C. In this venue we are concerned with parents' reports of their children's sadness, unhappiness, or depression (in a non-clinical sense) as opposed to depression as a clinical diagnosis. We do not, therefore, have to rely solely upon clinical intervention and assessment to address the disparity. Rather, a broad range of interventions may be relevant and effective.

II. What are the major *problems* in addressing this objective?
A. *As a general overview*, the critical challenges that confront us include the following.
1. Broad aspects of our prevailing culture are antithetical to the mental health of children in general and particularly destructive for children with chronic conditions or disabilities.
2. A school climate exists in many districts in which students subject any child who appears "different" to abuse ranging from ostracism to ridicule to assault.

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[*] Source: National Health Interview Survey (NHIS)

3. As a broad tendency, key service-delivery systems ignore the mental health needs in children with physical disabilities, and underidentify:
   a. mental health conditions in children;
   b. broad, societal interventions to promote positive mental health; and
   c. clinical services to treat those with manifest mental health problems.
4. There is a lack of instruments, training, and financing to identify children with mental health service needs, and a lack of access to and use of those services.

B. A broad range of examples of more *specific problems* must be recognized in addressing this objective. These problems reflect the general, societal neglect of child mental-health needs as well as specific barriers to primary, secondary and tertiary intervention in addressing mental health needs among children with disabilities. We determined the following problems.
1. A "depressogenic" culture that present images and messages that lead children to feel bad about themselves. These images and messages, such as those often reflected in the media are particularly destructive for children with disabilities.
2. Narrow definitions of eligibility for specific mental health (and other) programs that restricts access and use such that only those who are "truly needy" (e.g., those with diagnoses) are served; thus there is limited opportunity for primary and secondary mental-health prevention efforts.
3. The need for interventions that target both environmental and individual factors affecting mental health. Environmental intervention is particularly difficult since it involves changes at the societal level.
4. A lack of parity in reimbursement for health needs above the shoulders (e.g. oral, optical), and especially mental health versus physical health services.
5. Managed-care restrictions on mental health benefits.
6. Among disability groups, there is frequent competition for scarce resources.
7. A lack of reliable and valid clinical tools for screening or risk-assessment purposes that can be used in nonmental-health settings, such as schools and by primary care physicians.
8. A lack of training about mental health for teachers, primary care providers (including family practitioners and pediatricians), etc.
9. A tendency to focus on the primary condition of children with disabilities and ignore mental health disorders as a secondary condition.
10. A need for continued and expanded leadership at the national level (beyond the Office of the Surgeon General) around children's mental health.
11. Parental mental health needs

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

Potential partners for this objective include:
A. Parent groups and advocacy (both diagnosis-specific and cross-disability)
B. Child and mental health workgroups from the other *HP 2010* chapters, and those involved in implementing the Surgeon General's initiative
C. Professional organizations (e.g., the American Academy of Pediatrics)

D. School personnel and state departments of education
E. Those in higher education who are involved with training relevant personnel and young professionals
F. Corporations (particularly industries that profit from production of disability-related goods and services)
G. The media
H. Federal and state partners in the areas of mental health, public health, law enforcement, and child protection
I. Faith-based communities
J. Private nonprofit organizations
K. Private and public insurance companies that need to reimburse for child mental health services

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Policy and program changes to meet the mental health needs of children require:
   1. Acknowledging the universal need for individualized supports by families of children with chronic conditions.
   2. Assuring public funding for child mental health services. Multiple program initiatives can contribute to achieving this objective, including both broad interventions (which are available on a population basis for children, particularly at transition "sites" or "points" that place children and families at high risk), and interventions targeted to individuals with specific mental health problems.
   3. In-school education campaigns to improve tolerance of children who appear "different" for any reason, and "no tolerance" policies regarding bullying and other abusive behaviors; this is particularly needed at the middle school level.

B. Four key policies to promote achievement of the objective would be to:
   1. Adopt the United Nations Convention on the Rights of the Child,[1] that defines response to the health needs of children as a basic societal responsibility.
   2. Create a national policy recognizing the universal need for individualized supports by families of children with special health care needs. This concept builds upon, but surpasses, the American Academy of Pediatrics' (AAP) "medical home" concept.[**]

[**] A medical home is a central source of care for a child with special health care needs (cshcn), from which the child receives (at the least) primary care and care coordination. Care coordination in this context includes direct linkage to and follow-up with specialty and therapeutic health services to address geographic accessibility; continuity of care, comprehensive care (preventive well care as well as illness care). In addition, a medical home provides assistance with the planning and organization of other services (related to school, insurance, public benefits, and other nonmedical systems) required by the child and/or family. Given the complexity of some children's health and social needs and the central role families play in the care of cshcn, a clinical practice must be aware of the full range of the child's health and related needs and have an effective partnership with the child's family if it is to provide an effective medical home for the child.

3. Create means by which multiple government and societal sectors (including, but not limited to, public health) will formally recognize that child mental health is a shared responsibility and not "someone else's" job.
4. Achieve parity in insurance coverage and benefits for mental health and other health services, and secured financing of mental health programs.

C. Proposed program initiatives are:
1. Replicate the Early Intervention model for other age groups. This model combines family services, family-to-family support, and therapeutic services for the child in a setting that is as integrated as feasible. The model may be particularly important for children with disability and their families at key transition sites/points such as growing from preteen to teen, or moving from school into work.
2. Fully implement Early Periodic Screening, Diagnosis and Treatment (EPSDT), both as a source of financing and as a programmatic base for providing all medically necessary services, including mental health, for children with special health care needs.
3. Implement mental health promotion programs for children with special health care needs (cshcn) through many types of community-based settings (e.g., schools, faith-communities, park districts).
4. Maximize inclusion in socialization programs, including programs with peers without disabilities and programs that are provided exclusively for children with disabilities.
5. Train multiple professional groups about mental health issues and needs. Such training should include the ability to identify children with mental health conditions or risks.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

We recommend that NHIS data and other comparable data sources be used to monitor the impact of these recommended activities.

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Objectives 6.3: Reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness, or depression that prevents them from being active

Introduction
The workgroup fully endorses the objective. In order to accomplish this objective, work must be done to address issues at both the individual and environmental (societal) levels. Individuals with disabilities are likely to have multiple and unique issues that may contribute to states of unhappiness, sadness, and depression.

I. How *practical* are the targeted objectives for implementation by the year 2010?
It is important to note that the words in Objective 6.3 that emphasize "depression" and "unhappiness" are not specified in the NHIS survey question (Adults Core CAN.471).[*] There is a concern as to how easily the terms transfer to the objective. The objective, however, focuses on emotions that may inhibit participation.

The 7% target (parity with the general population)[1] appears to be unrealistic for the following reasons:

A. This objective is calling for reducing from 28% to 7%the proportion of people with disabilities who report these emotional states —a 75% reduction and improvement. A lowered expectation, in part, would include the observable predominance of emotional-state risk factors based on race, age, income, gender, and educational level.
B. A 28% baseline would seem to be too low for the disability group. Some research suggests this figure may be much higher—perhaps as high as 59% or greater, especially for women.[2]

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[*] _**CAN.471:**_ During the PAST 30 DAYS, how often did you feel
   …so sad that nothing could cheer you up?
   nervous?
   restless or fidgety?
   hopeless?
   that everything was an effort?
   worthless?

        ALL of the time
        MOST of the time
        SOME of the time
        A LITTLE of the time
        NONE of the time
        Refused/Not ascertained/Don't know

[Asked of person who at least some of the time have felt "sad; nervous; restless or fidgety; hopeless; that everything was an effort; or worthless" in the past 30 days.]

_**AC. 530:**_ We just talked about a number of feelings you had during the PAST 30 DAYS. Altogether, how MUCH did these feelings interfere with your life or activities: a lot, some, a little, or not at all?

C. There should be a re-analysis to examine the case definition of disability status (the denominator) for this item to determine if a finer and narrower definition would be more valid.

II. What are the major *problems* in addressing this objective?
We have identified four areas in which problems exist for addressing this objective.

A. Assessment
1. Address both the broader societal issues and the individual clinical level contributing to depression. The current assessment tool does not utilize a clinical measure that suggests the severity of depression nor does it identify the environmental factors that may influence the outcome. Assessment should also evaluate the root causes of depression and sadness, and clarify real operative issues, such as the consequences of environmental, biologic, or situational problems.
2. National questionnaires that can identify the overlap of disability and other issues must be developed; advocate for developing another NHIS disability supplement.
3. Develop and validate instruments for assessing depression in the context of disability.
4. Develop valid tools for assessing emotional states and obtaining proxy reports for persons with significant cognitive limitations who may not reliably report emotional states or answer questions about their experiences using existing standardized instruments or measures.

B. Unavailability of prevention and treatment services
Funding support is needed to increase the availability of effective support services including reimbursement mechanisms that would facilitate widespread implementation of, access to, and use of such services and treatment.

C. Empirically-based information needed
Depression within the context of disability (i.e., depressive features as they may present and be managed in people with disabilities) has not been adequately investigated. Research will help to:
1. Conduct clinical trials to evaluate prevention and treatment interventions, targeting key correlates of depression in the context of disability (e.g., income, education, perceived stress, disability specifics, fatigue, pain, abuse, and social isolation).
2. Develop and evaluate training programs for mental health providers and other providers who are often not trained to recognize mental health issues in the context of disability.
3. Raise general public awareness and therefore help to reduce stigma about emotional problems that might be addressed through intervention.
4. Build on the existing knowledge base, and develop and test mechanisms of change (e.g., role of self-determination).

D. Disability culture
In general, people with disabilities are optimistic about the future but pessimistic about what will happen for them as individuals.[3]

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective? (Table 1)

The theory of "just societies" tells us that for justice to occur, change must happen on every level; therefore, partners are necessary across the board.

A. From an environmental (societal) perspective—those who are involved in supporting structures for self-advocacy and for changing the world in which we live—partners would be those involved with transportation, housing, poverty programs, health delivery, architecture, employment, childcare, and education.

B. Programs that are designed to meet the largely individual needs of people with disabilities include state mental health agencies, disability-related agencies, vocational rehabilitation entities, health care entities, and Centers for Independent Living.

C. In addition, all workgroups for *HP 2010* Chapter 18 (Mental Health and Mental Disorders), and those working on other *HP 2010* objectives[*] should be considering the needs of people with disabilities in their deliberations and plans.

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[*] Other Chapter 6 objective workgroups that should be addressing these issues are Objectives 6.2 (Child Mental Health), 6.4 (Social Participation), 6.5 (Emotional Support), and 6.6 (Life Satisfaction).

Table 1.—Partners in Addressing Individual and Environmental Variables of Objective 6.3

	Partners in Addressing Individual Needs and Providing Treatment Services	*Partners in Addressing Environmental Variables*
Local	Centers for Independent Living (CILs) Mental health centers Churches and other faith-based communities, to provide counseling and referrals Private practitioners Shelters (for the homeless, battered partners, etc.) Veteran's Administration (VA) Employee Assistance Programs (EAP) Personal assistance and home health agencies Area agencies on aging	Centers for Independent Living (CILs) Alliance for the Mentally Ill (AMI) People First Churches and other faith-based communities The media
State	State Councils for Independent Living (SCILs) Vocational Rehabilitation Councils State offices of mental health State mental retardation/DD offices Area agencies on aging	State Councils for Independent Living (SCILs) Developmental Disabilities Councils AMI People First The Arc The media

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Programs that work and issues for consideration

Programs for depression target three levels: 1) an individual level, 2) a social-support/interpersonal program level, and 3) an environmental change level. In this last type of program, attention is shifted from the self and this helps to increase the opportunity for personal satisfaction; thus, people with disabilities can find that their involvement in advocacy becomes personally meaningful.

1. At the individual level, stress and social isolation are associated with depression.
   a. Programs are needed to help individuals develop self-management skills and make social connections. Policies and programs in this area will need to be coordinated with those recommended by the workgroups for *HP 2010* Objectives 6.5 (Emotional Support) and 6.12 (Environmental Barriers).

b. Empirically demonstrated packaged programs that can be delivered by professionals, paraprofessionals, consumers, and peers include those described by Lorig,[4] Ravesloot,[5] and Seligman.[6] Research initiated at the University of Houston[7] involves a program that may be broad enough to use peer interventionists to teach self-management therapy for the behavioral management of depression. Designed for the general population, this program could be modified for people with disabilities, using peer-led groups evaluated at CILs and in rehabilitation and community settings.

2. At the societal level, injustices lead to conditions that promote depression. Efforts to address social justice reduce prejudice and discrimination, which can help ameliorate feelings of alienation and isolation, and may promote a sense of dignity and belonging.

3. When people participate in programs in which they feel fully engaged, they begin to report fewer barriers to participation.[8] This suggests the importance of addressing emotion as a barrier.

4. When implemented, concrete programs for assisting people with housing and transportation work well in contributing to improved emotional status and participation.

B. Programs that address the individual and environmental levels to reduce sadness, unhappiness, and feelings of depression experienced by people with disabilities.

Programs can be viewed as those that address more specific individual levels of effect or those that target social or environmental activity.

Individual level
1. Screening needs to be recognized as important for identifying depression, but an easy, simple, and cost-effective method should be developed that does not put the sole responsibility for screening on primary care providers.

2. Health care providers and others need to have a greater awareness of depressive symptoms and be reinforced for client/patient referrals. The relation of affect (emotions/anxiety, depression) to behavior (social participation) must be included in their assessments.

3. Provide training in disability issues to cross-cut professional-service providers so that they come to understand the inherent risks and response strategies.

4. Web-based self-management needs to be developed but there should be "certified" Web sites that present useful information for consumers, family, and providers. Models such as Consumer Reports or validation checklists might be used for certifying these sites. Accessibility and usability criteria should be used to assess the information provided in these Web sites to ensure that parity is possible for people with disabilities. One example of this is availability of information via a screen reader; another is the Web-based self-management program for exercise provided by the National Center on Physical Activity and Disability (NCPAD).

5. Increase consumer awareness and training so that there is greater understanding and potential for evaluating information on the Web that purports to "treat" mental health.

6. Develop instruments and methods that can measure depression and stress related to cognitive and communicative impairments (e.g., the learning domain) within the population of individuals with disabilities.

7. Institute reimbursement policies that would "make prevention pay," such as Medicaid policies that provide adequate compensation for professional providers but also incorporate reimbursement of "peer counselors" who deliver demonstrated programs (e.g., *Seligman's Learned* Optimism[6] and other packaged programs such as *Living Well with a Disability*[5]).

Social and environmental level
1. The Department of Transportation (DOT) should revisit its national assessments of access to and use of transportation by households without cars in order to assess, in particular, the access by people with disabilities and the uses of transportation. Include a minimum assessment of the effects of access or lack of access on quality-of-life (QOL) issues.

2. Programs are needed to help provide accessible and usable housing. When people are able to live independently, their emotional health and social participation can be improved.

3. All recreation programs (city, county, YMCA, etc.) should be accessible and usable, and there should be a means of assessing the status and methods of implementing changes, and a method of monitoring the degree of change over time.

4. Solutions for environmental barriers, more programs, and greater participation of people with disabilities are all needed. Population-based change in universal design is also needed.

5. City and regional planning groups should be brought into the role of ensuring that buildings meet accessibility and usability guidelines.

6. The media need to be rewarded for their progress and should continue to be exhorted to provide a positive portrayal of disability to the broad public. People with disabilities also need to be a part of the media. The NIDRR-funded project "Accessible Society Action Project" offers one model of increasing media awareness of disabilities.

7. Work to "equalize" Medicaid policies so that they will offer mental health services that address this objective's problem. The primary way this is likely to be achieved—by providing reimbursement for both individual and group services—is to get this coverage requirement included in the basic package that all states must demonstrate in order to qualify for Medicaid participation.

8. Employer-based wellness programs need to include components that address disability and the needs of people with disabilities.** This is consistent with employer movements to maintain employees as a cost-management and productivity strategy.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

As a foundation for tracking this objective, we recommend adequate mechanisms be identified or devised to address the "case counting" problem. We recommend using standardized instruments (i.e., NHIS) primarily, but we also strongly recommend considering adding federally mandated or federally supported special surveys among persons with specific types of disabilities. For example, we suggest using surveys that will bring to light existing limitations of activity, communication, self-care, and learning—that is, surveys that incorporate 1) the NHIS question (Adults Core CAN.471), *and* 2) standardized instruments of behavior and emotional problems, *and* 3) some special questions that are designed for disability-specific limitations. In our judgment, this is what needs to be done to better determine the reliability and validity of the NHIS question. We recommend repeating the NHIS disability supplement in the future.

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** Employers, as well as childcare and education, are also important partners at the local (individual) level. Employers could be given incentives to retain employees and to keep workers productive. The cost of rehiring and training is substantial, as are costs from missed days at work. Employers increasingly are scrutinizing the productivity of workers and they have every reason to be interested in retaining good employees and offering services or programs that will ultimately enhance independence and productivity. As one example, people with disabilities may need more health-related time off. If this could be understood and negotiated by the employer at the time of hiring, individuals would not be dismissed as often, thereby saving money that the employer might have spent in rehiring and training.

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Objective 6.4: Increase the proportion of adults with disabilities who participate in social activities

Introduction

We believe that life, liberty and the pursuit of happiness are intricately connected to social participation. Social participation is critical as an indicator of health and well-being, especially given that humans are innately social creatures.

I. How *practical* are the targeted goals for implementation by the year 2010?

Target: 100 percent

Baseline: 95.4 percent of adults aged 18 years and older with disabilities participated in social activities in 1997 (age adjusted to the year 2000 standard population).

Although we fully endorse Objective 6.4, the target for objective is impractical because the current survey item used to assess that goal is neither valid nor sensitive. We believe that the proposed measures (see below, 6.4 section V.) are practical; however, they will require investigative work to further define these measures, their goals, and their ongoing practicality.

The issue of practicality must be addressed in at least two areas: 1) achievability of the target in terms of ambitious expectations, and 2) achievability based on available legislation, infrastructure, resources, knowledge, ongoing efforts, history of progress in this area.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch (DHB) have concluded an agreement by which data to measure this objective is included in BRFSS National Health Interview Survey supplement during 2001. New baseline data will be available in 2002.

II. What are the major *problems* in addressing this objective?

A. The gold standard or goal for the desired outcome for social participation is currently undefined.

B. There are known barriers that relate to increasing social activities among adults with disabilities. These barriers include:

   1. Inadequate transportation
   2. Architectural barriers
   3. Policy and practice barriers, such as those that lead to unemployment and underemployment
   4. Communication barriers

5. Attitudinal barriers; examples are health care providers who do not consider social participation to be as important as other clinical outcomes; or people with disabilities may not *feel* welcome to join in activities, so that attitudinal barriers may be two-sided in terms of their impact.
6. Health conditions (physical and mental health) that impact social participation
7. Unsafe, inaccessible and segregated low-income housing
8. Inadequate school-based opportunities for social participation during and after hours

C. A position paper needs to document the scientific basis of social participation as essential to the health and well-being of all people including people with disabilities.

D. An additional problem for this objective is the fragmentation of government-based funding streams for disability risk assessment and intervention research, training, and information dissemination.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. *Government partners*
1. Congress
2. Research agencies and institutes such as the National Institutes of Health (NIH), National Institute of Disability and Rehabilitation Research (NIDRR)
3. Agency for Healthcare Research and Quality (AHRQ)
4. National Council on Disability (NCD)
5. Departments of Transportation (DOT), Labor (DOL), Justice (DOJ), Education (DOE) the Interior (DOI), Health and Human Services (DHHS), and Housing and Urban Development (HUD)
6. Veterans Administration (VA)
7. Small Business Administration (SBA)
8. E-health (Web based) efforts
9. State Assistive Technology Act Projects (ATAP)
10. President's Committee on Employment of People with Disabilities

B. *Nongovernmental partners*
1. *Foundations* such as the Robert Wood Johnson Foundation. (This would call for a strategic and sustainable joint research agenda.)
2. *Social organizing groups* including the NAACP (National Association for the Advancement of Colored People), National Council of Churches (NCC), National Organization of Women (NOW), AARP, La Raza (Hispanic Health Group) and National Indian Health Board (NIHB)/National Congress of American Indians (NCAI).
3. *Disability-related advocacy organizations* include the National Council on Independent Living (NCIL), Psychiatric Survivors, National Association of Mental Impairments (NAMI), Consortium for Citizens with Disabilities (CCD), United Cerebral Palsy

Association (UCPA), The Arc, Association of Programs in Rural Independent Living (APRIL), National Organization on Disability (NOD), Amputee Coalition of America (ACA), and others.

4. *Organ-specific and health/disease-specific groups* include organizations such as the American Heart Association (AHA), American Lung Association (ALA), and American Cancer Society (ACS).

5. *Labor unions, and public and private groups addressing generic health promotion*, are other potential partners in this category.

C. *Private partners*
1. Managed care organizations and other health insurance companies
2. Recreational programs, both public and private (e.g., parks, health and fitness facilities)
3. Health-related self-help groups (e.g., Weight Watchers, Jenny Craig, 12-Step programs)
4. E-health companies
5. Auto manufacturers as a group
6. Employee Assistance Programs (EAP)
7. Sports, recreation, travel, and entertainment industries
8. Media and advertisers: regarding portraying people with disabilities (in television series and advertisements) as socially participating
9. US Chamber of Commerce
10. US Better Business Bureau.

D. *Other partners*
1. Professional health and health care associations
2. Academic partners
3. Health care accrediting bodies, such as the National Council on Quality Assurance (NCQA) and Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
4. Groups devoted to topics associated with complementary medicine

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Technology and environment
1. Allocate more resources to enforcement of current legislation to promote full access and social participation of persons with disability (i.e., disability civil rights laws). Governments at the federal, state, and local levels should provide leadership in implementing full access to buildings, programs, and services. That is, government buildings and programs must provide reasonable accommodation for people with disabilities.

2. Investigate, document and disseminate best practices in the for-profit sector working for universal design to bring to bear the cutting edge of private sector entrepreneurship as quickly as possible.

3. Promote research and development in technology transfer. This will help make assistive technology widely available as soon as possible.

4. Institute universal design of equipment and structures in educational settings.

5. Promote broader accessibility in information technology such as Web-based information transfer through regulatory and incentive procedures.

B. Financial incentives
1. To help achieve full social participation of persons with disabilities, encourage businesses to take advantage of existing incentives (tax credits and deductions). Without these incentives, this is a low-priority focus for these entities. Cost can be a significant barrier to businesses aggressively engaging technologies and methods with the purpose of increasing participation. Support 1) research about cost-effective ways that accessibility and usability can be incorporated with 2) aggressive information dissemination to local community businesses. Show businesses that universal design is good business. For example, the test talkers/email that was originally designed for people with hearing impairments is now a communication standard. Universal design can be a better and more marketable design.

2. Provide a non-itemized tax credit to adjusted gross income for disability-related expenses. With such a proposed deduction, people who do not itemize their taxes can also benefit. This will encourage providers proactively to recommend, prescribe, arrange, and support appropriate assistive services.

3. Reduce the percentage of medical expense exclusion necessary for medical deductions. Lowering threshold levels for individual taxpayers to qualify for tax relief for assistive technologies will enable and encourage more individuals to access and use these technologies.

4. For persons with disabilities, provide tax credits and loan policies for procuring goods and services that promote social participation (e.g., vans, assistance services, assistive technology, etc.). Rather than offering these amenities as a charitable gift, they would be targeted to those people with disabilities who have high disability-related living and health expenses.

C. Professional issues: assessment and training
1. Encourage the health care professions to include assessment of social participation/support, in addition to mental and physical health, as part of routine care, and address funding issues that would facilitate such assessment.

2. Consider the implications for training health professionals about increasing social participation of persons with disabilities. Create links to programs in the generic health care disciplines to infuse these concepts into training.

D. Community incentives
1. As part of diversity and cultural competence considerations, promote broader inclusion of people with disabilities; for instance, include the provision of interpreter services in social and recreational activities.

2. Allow universities and colleges to be included as eligible for the community development grants that encourage the social participation of persons with disabilities.

3. Create incentives for places of worship and other community-based organizations to perform outreach and support the participation of persons with disabilities.

4. Create mechanisms for funding support to engage people with disabilities in programs of the arts, sports, etc.

E. Perspective and leadership
Encourage the perspective of societal participation as integral to health. Stabilize and enhance a lead role for CDC Disability and Health Branch to coordinate federal agencies that are addressing issues of disability and health.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

Mechanisms for tracking progress of social participation are inadequate. The proposed measures are not part of a current data-collection system. They would require development, pilot testing, and implementation with the endpoint built into a core, national, ongoing surveillance system. Surveillance systems that rely on telephone surveys without adequate accommodation for persons with communication needs, as well as other impairments (e.g., BRFSS), are not adequate as a single measure.[1]

> **March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch (DHB) have concluded an agreement by which data to measure this objective is included in BRFSS National Health Interview Survey supplement during 2001. New baseline data will be available in 2002.**

As currently constructed, the *HP 2010* measure of social participation does not adequately reflect social participation or quality of life. The calculated baseline measure of 95.4 % is too close to the target of 100% participation to be able to document real change. Furthermore, the current measure for this objective is, in actuality, a measure associated with disability only as it is an indicator of assistive technology utilization. (See March 2001 status update boxes in this objective paper).

To address the problems cited above, we propose that newly developed measures uphold the following principles.
1. Measures need to be valid/relevant such that they measure social participation.
2. Behavior and expectation measures need to measure self-reported social participation (Yes/No or frequency), and reflect relative perception—that is, satisfaction as it is demonstrated by the level and/or diversity of the participation.
3. Measures need to capture the diversity of social participation—i.e., work, leisure, family, friendships, and community life (such as politics, worship, recreation, and volunteering).
4. Measures need to reflect informed, self-defined expectations as well as community opportunities. In other words, analogous to the saying "A fish doesn't know it's in water," people with a disability can only truly assess their level of participation relative to a standard that includes opportunities available to everyone.
5. Measures need to be sensitive to change.
6. Every culture has a different attitude about its members who have disabilities participating in social activities. Addressing this problem will have to be culturally specific.

The following are proposed as "straw" measures that exemplify the aforementioned principles. These measures will require further exploration to yield psychometrically sound measures with data-based standards/goals. These serve only as examples of potential measures and standards.

"Straw" measure #1: Number of social participation activities in two (2) or more of the following categories in a week—work, leisure, recreation and sports, gatherings of family and friends, social clubs or hobbies, community events or gatherings, Internet chat rooms. Standard/Goal #1: 75% of people participate in 25 or more activities per week.[2,3,4]

"Straw" measure #2: How satisfied are you with your social activities? (The measure is achieved using a four-point Likert scale). The Standard/Goal #2: 85% of people report 3 (somewhat satisfied) or 4 (satisfied).

VI. Recommendations
1. A legislative mandate and funding for ongoing monitoring should be assigned to CDC.
2. Consider alternative extant data collection methods such as those associated with the Social Security Administration (SSA), University Affiliated Programs (AAUAP), and the Maternal and Child Health Bureau (MCHB).
3. Explore the development of community accessibility and usability profiles for potential use in *Healthy People 2020*.
4. As with all *HP 2010* objectives and measures, these profiles should be reviewed regularly for ongoing relevance.
5. The new question(s) to be included in the 2001 National Health Interview Survey supplement (one is provided here under 6.4, section V), will provide a stronger mechanism for tracking progress.

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Objective 6.5: Increase the proportion of adults with disabilities reporting sufficient emotional support

Assumptions
Recognizing that an individual's social support system varies depending upon a person's age, a life-span approach is fundamental when assessing whether individuals are receiving sufficient emotional support. Transitional programming will need to be outlined to assist people with disabilities who are moving between and through life stages, particularly adolescence and the aging process. These changing life stages involve learning new personal and social roles, knowledge (e.g., about sexuality and peer relations), personal awareness, and individual and societal expectations. Problems in moving thorough life stages and roles can be catalysts for becoming socially isolated or excluded. There are also strong cultural elements in how we define social-emotional support. We realize that placing emphasis on the development of natural supports (people who are already in the lives of people with disabilities) is essential to providing emotional support, as is the role of spirituality.

Introduction
Emotional support often is derived from a person's social support systems. Research suggests that social support helps a person cope with stress and that supportive relationships may serve as a protective factor in various life situations. Emotional support has also been found to be a factor that may protect against unhealthy outcomes such as heart disease, complications of pregnancy, and depression. Objective 6.5 calls for parity in reporting emotional support between people with and without disabilities. Achievement of this objective should reduce health disparities between these populations and improve the quality of life for people with disabilities. Through monitoring the personal perspective, the US may better address policy and programmatic efforts that reinforce and enhance the social supports available to persons with disabilities.

We wish to clarify that this objective relates to the social-emotional support, community access, and social participation of individuals with disabilities. Therefore, see also the workgroup reports for the *HP 2010* Chapter 6 objectives related to community access: Objectives 6.4 (Social participation) and 6.12 (Environmental barriers).

In addition to physical environment, another crucial area for examining emotional support is the communication environment. The burgeoning technologies that now allow communication via interactive means, such as cyber-support groups, must be included and investigated for accessibility, usability, and availability. Investigational research on these technologies should incorporate issues relevant to people with disabilities.

Accommodating such a reorientation would encompass issues of family support, caregiver needs, independent living, personal stress reductions, community-based participation, and spirituality.

It was our opinion that national data sets serve mostly as "beacons" of social conditions rather than attempting to be true research instruments. That is, although these data instruments can be modified to increase sensitivity to these dimensions, as they exist, they should not be relied upon

as a sole source in monitoring. These instruments currently could only hope to measure social inclusion or social integration status on the broadest of levels—that is, by prevalence. Thus, these instruments could "beacon" a possible trend, but they could not replace "cause and effect" investigations.

I. How *practical* are the targeted objectives for implementation by the year 2010?
This is a practical objective that is measurable through BRFSS. However, implementation of this objective would entail dramatic changes in the supports available to persons with disabilities and their caregivers. In addition, implementation of this objective would require significant financial resources. Implementation may be costly due to the recognition that emotional support is a community-wide phenomenon. Emotional support could be viewed as an actual rationale for the formation of communities. Yet, it would be a major program effort for a community to recognize that for some of their members—that is, people with disabilities—isolation or being ostracized might be the reasons that emotional support, social inclusion, or social integration were not being achieved. To attempt to ameliorate these attitudes or circumstances would add further to the cost of these endeavors.

II. What are the major *problems* in addressing this objective?

A. Financial resources will be required to 1) implement both program services, and 2) evaluate social supports including the expansion of BRFSS with other more sensitive and program-specific measures.

B. Disparity issues related to disability are complex. People with disabilities, like other groups that have been historically disadvantaged, have higher rates of unemployment, lower incomes, and lower educational attainment than the general population of adults. Although the Americans with Disabilities Act (ADA) was created to address many of the barriers to participation in society, full implementation has not been realized.

C. People with disabilities often encounter significant structural, financial, and personal barriers that limit their access to and use of support programs and services. Accessibility and usability barriers may be further compounded for individuals with disabilities who are poor; elderly; are members of racial, ethnic, cultural or linguistic minority groups; or who live in rural areas. Like other high-risk minority populations, the characteristics, and social and emotional needs and experiences, of different segments of the disability community must be taken into account in crafting effective interventions. In some cases, new strategies will need to be adapted or developed, particularly to address the physical, attitudinal, and educational accessibility and usability of programs and services.

D. This definition must be sensitive to diversities of culture, ethnicity, gender, age, and sexual orientation such that people with or without disability (as a group) who are experiencing decreasing social integration, can be appropriately monitored.

E. Implementation will require creating and identifying data "beacons" within national instruments to identify decreasing social interactions among target populations within community settings (see Objective 6.1).

F. For any initiatives to resolve the social isolation of people with disabilities, and in order to garner broad-based public understanding and support, it will be important to address the media. The NIDRR-funded project "Accessible Society Action Project" offers one model of increasing media awareness of disabilities.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. Coalition of agencies

To implement this objective, it is important to develop a coalition of agencies to assess and address the inherent problems, and to develop a blueprint to accomplish parity. We suggest that involved partners also devise methods of increasing emotional support within the family unit, and among family caregivers and other caregivers, for the purposes of peer support and religious/spiritual support. Activity management will vary at federal, state, or local levels (i.e., government, nongovernment, private, and commercial levels). Certain federal and state groups and organizations, which act as "enabling powers," will need to allow local activities to be designed to address these social integration issues. Developing social integration programs may take considerable time, and thus may not easily stay up-to-date with the evolving needs of people with disabilities.

B. Potential partners in eliminating disparities and focusing on social and emotional support

1. *Government partners* would include public health offices (at all levels); all population-centered agencies; all other agencies involved with societal support, assistance, and services for citizens (such as social services, education, labor, transportation, etc.).
2. *Nongovernment partners* would include the Centers for Independent Living (CILs); disability advocates including affiliates of national organizations and singular advocates, and target-population (minority and cultural diversity) advocates; insurance carriers; and commercial enterprises (such as retailers, the food and beverage industries, and entertainment groups).
3. *Private partners* would include employers; social recreation and fitness programs and agencies; churches/faith-based communities; foundations; and the media.

C. Recommendations for partners

We recommend including the following groups as the core of this partnership initiative.

1. The public health community, including national, state, and community programs across the spectrum of services (i.e., chronic disease, children with special health care needs, women's health, developmental disabilities services, etc.).
2. Centers for Independent Living (CILs) and other disability advocacy and service organizations

3. Private partners and faith-based communities
4. The academic community, i.e., colleges and universities

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

Transitional programming will need to be outlined to assist people with disabilities who are moving between and through life stages, particularly adolescence and the aging process. It will be necessary to devise surveys and reporting measurements that are responsive to the breadth and diversity of a definition of social-emotional support.

The life-stage transitions that are experienced by community members, regardless of the presence of a disability, are key points for prevention programming. These transitions include progressions through the educational system, stages of puberty, employment stages, marital stages, parental stages, etc. With the lack of role models (including cultural role models) for people with disabilities, these transition sites may not be negotiated successfully and thus may result in a decrease of emotional support and social integration or inclusion.

Programs that would promote social-emotional support and community participation include the following.
A. "Disability awareness" activities targeted to the Media and communities

B. Initiatives to improve accessibility and usability of both the physical and communication environments, and that promote universal design in both.

C. Programs that develop and expand Personal Assistance Services (PAS). These are a range of services that address the needs of some people with disabilities, and that can be obtained in many ways including with government funding. Expansion of PAS would allow persons with disabilities to participate fully in the community, for example, in attending and participating in faith communities; social functions; and family, leisure, and recreational activities.

D. Programs that expand Respite Care Services (RCS)—again, a range of services (see #3 above) that provide support to persons with disabilities and their caregivers—will also facilitate attending and participating in faith communities; social functions; and family, leisure, and recreational activities.

E. Programs that address other government disincentives to community inclusion and gainful employment (such as Medicare homebound restriction).

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

The annual BRFSS disability module, the baseline for this objective, will track progress in meeting the targeted goals in the 11 states that currently use the disability module. Work and funds will be required to institute the use of these questions (the disability screener questions, and emotional and social support questions) in BRFSS of all 50 states.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch (DHB) have concluded an agreement by which data to measure this objective is included in BRFSS National Health Interview Survey supplement during 2001. New baseline data will be available in 2002.

C. Concern
While BRFSS and NHIS will measure self-perception, more sensitive and comprehensive measures must be devised to determine how best to meet this need and measure program effectiveness.

Objective 6.6: Increase the proportion of adults with disabilities reporting satisfaction with life

Introduction
As it is with building a road, if any section is incomplete, it is hard to arrive at one's destination. Likewise, without achievement of most of the other *HP 2010* Chapter 6 and related objectives, the life satisfaction objective cannot be reached. Life satisfaction is a composite picture of how well we are doing with Chapter 6 objectives. We feel that Life Satisfaction (LS) is a cumulative index, perhaps even more than the sum of its parts. Life satisfaction is closely related to Quality of Life (QOL), another broad term. Although there are probably technical differences between these terms, we are choosing to use them interchangeably in this report.

Assumptions
Before addressing the responses to the five questions asked of all workgroups, several general issues need to be viewed as a backdrop for life satisfaction.
    A. Research has shown that people without disabilities project lower QOL for people with disabilities—lower than people with disabilities rate their own QOL. This presumption affects the way that people without disabilities perceive and interact with people with disabilities. Furthermore, the "self-fulfilling prophecy" takes place whereby people with disabilities may lower their self-concept, thereby undermining self-rated satisfaction with life.
    B. Poverty and education were also suggested as significant factors that affect life satisfaction. Studies indicate that people with disabilities are more likely to be poor and have less education than people without disabilities; these circumstances undermine satisfaction with life.
    C. Trends show an aging population, and while staying fit as you age is becoming popular, the sheer number of older people living longer points to more people who are experiencing disabilities. This large segment of the US population will likely respond to the current inaccessible environment in the form of decreased population satisfaction with life. The 2000 Harris Survey[1] demonstrates this by reporting life satisfaction by age. The overall gap in reported life satisfaction between people with (33%) and without (67%) disabilities is 34 percentage points. However among 18-29 year olds, the gap is only 13 percentage points.
    D. The Harris Survey[1] indicated that 41% of people with disabilities expect their lives to get better over the next 4 years as compared with 76% of people without disabilities. This QOL projection differs by age group, but will certainly correlate with life satisfaction reports.

I. How *practical* are the targeted goals for implementation by the year 2010?
We feel that gaining parity of reported life satisfaction between people with and without disabilities (96%) by 2010 will be difficult to achieve. We believe that there are substantial societal changes that must be made, and that society is not ready to change that quickly. This is a long-term goal that is and will be affected by education and work environments, societal attitudes, assistive technology, environmental barriers, emotional support, and other topics for objectives within Chapter 6. These objectives represent many of the factors that contribute to

life satisfaction. Because many disability policy issues have been languishing for 25 years, it is difficult to estimate what a reasonable goal would be for the next 10 years. It is, however, a matter of social justice that parity be the goal of the objective so that attention is continually drawn to the need.

II. What are the major *problems* in addressing this objective?

1. Data are a problem when tracking this objective. There is a lack of consensus on what constitutes life satisfaction and the best tools to measure LS for people with or without disabilities.
2. There are also inadequate resources for collecting accurate data, particularly at the local level; this is a universal problem with surveillance data.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch (DHB) have concluded an agreement by which data to measure this objective is included in BRFSS National Health Interview Survey supplement during 2001. New baseline data will be available in 2002.

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3. There may well be differences across disability groups, such as those pertaining to congenital versus acquired disabilities, mobility versus mental health disability, or differences by culture or age cohorts.
4. Societal attitudes toward disability and the media's presentation of disability contribute to conflicting and generally negative messages about disability and people with disabilities. Evidence of this feeling of shame is also present in other countries.
5. Cultures, as well as systems within cultures, such as organized religion, politics, etc., contribute to an atmosphere of disapproval of disability that may lead to a reduction in life satisfaction. It must be remembered that systems are created for the "greater good" as opposed to "individual good."
6. Cultural differences also need to be taken into account. For example, life satisfaction for individuals with disabilities who belong to ethnic groups, such as Native Americans and Alaskan Natives, is challenging due to even greater lack of resources on reservations and in villages.
7. Education: Because resources for complete implementation have not been forthcoming, the education system has not been able to implement the Individuals with Disabilities Education Act (IDEA).
8. Transportation: There continue to be significant problems in obtaining access to and use of affordable and accessible transportation both within and between communities. This service also contributes to participation and positive life satisfaction.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. Governmental partners
1. DOE, OSERS, Rehabilitation Services Administration (RSA), and NIDRR officials
2. Federal Interagency Committee on Disability Research
3. Department of Labor
4. DHHS and the Office of Disability and Health/CDC officials and researchers
5. NCD
6. State directors of education
7. State directors of public health
8. State directors of employment
9. State directors of vocational rehabilitation
10. State directors of community mental health
11. SILCs
12. HUD
13. DOT
14. Surgeon General's Office
15. Office of Disease Prevention and Health Promotion (ODPHP)
16. DOJ
17. HCFA
18. SSA
19. NCIL
20. APRIL

B. Nongovernmental partners
1. NOD
2. Washington Business Group on Health (WBGH)
3. CARF
4. JCAHO
5. CCD
6. American Association of People with Disabilities (AAPD)
7. Disability Rights Education and Defense Fund (DREDF)
8. AARP
9. Families USA
10. American Public Health Association (APHA)
11. State Independent Living Councils (SILCs)

C. Private partners
1. Employers
2. Insurance companies
3. Managed care organizations (MCOs)
4. Academic institutions
5. Foundations (e.g., Robert Wood Johnson Foundation)
6. The media
7. Internet E-health companies (e.g., WebMD)

8. Computer and technology firms (e.g., Microsoft)
9. Entertainment industry (movies, TV, etc.)
10. Advertising agencies
11. Advocacy organizations
12. Corporations (e.g., AOL-Time Warner, Sony)

IV. What are the initial *programs*, current or envisioned, and/or *policies* that could help meet this objective

Professional training programs in health care, journalism, and education should implement courses to enable their students to reassess their biases toward individuals with disabilities. The definition of and attitudes about disability are currently limited to the medical model. Training programs do not customarily provide a thorough and balanced look at individuals with disability.

A. National programs and policies
We recommend that the following programs and policies be undertaken at the national level:

1. Governmental
a. **Conference:** Conduct a national conference to develop research-based consensus on a definition of Life Satisfaction and identify factors contributing to positive LS along with recommendations for measurement.
b. **Legislation:** Work for passage of the legislation to increase programs for health and disability.
c. **Legislation:** Work for passage of Medicaid Community Attendant and Support Services Act (MiCASSA) legislation that permits Medicaid coverage for a longer period while a person is working.

2. Nongovernmental
a. **Program policy:** Encourage CARF, JCAHO, and the other accreditation organizations to include specific standards regarding the tracking of life satisfaction in existing program evaluation and quality assurance tools. The AHRQ's Consumer Assessment of Health Plans (CAHPS), and the CAHPS-PWMI (People with Mobility Impairments), produced in collaboration with NIDRR and the National Rehabilitation Hospital Center for Health and Disability Research (NRHCHDR), are good examples of this.

b. **Legislative and program policy:** Develop resources to assist local communities in identifying new, and addressing known, factors that affect life satisfaction.

B. Community-based/Local programs and policies
The issues are similar to those mentioned above, but they concern activities at the local level.

C. General program and policy recommendations
1. Work toward raising the expectations of people with disabilities. Those with disabilities need to expect the same things as those without disabilities, including the means for

ongoing personal development; that is: (1) find your identity, (2) strive to physically separate from your parents, (3) actively search for social supports and a peer group with which you can relate, (4) find sources of love and passion that come from inside yourself as well as sources in environment, and (5) seek and secure a vocation for economic independence. As a caveat, we must also recognize that personal needs might mean that there are different schedules in the rites of passage and although we may monitor such passages for individuals, there is no intent to proffer blame for being unable to meet the expectations of a prescribed time or sequence for such passages.

2. Fund and undertake a real evaluation of the health care system and what the incentives are, or should be, in the programs to include people with disabilities.

3. Establish a program that addresses the question: *"What do you want to be when you grow up?"* If we begin to ask children with disabilities—in a consistent way and as soon as they can understand that concept (that is, from toddler age on up)—what they want to be when they grow up, and give kids an opportunity to play at being "grown up," this will help children with disabilities to distinguish any feelings they may have of being limited in their aspirations and resources.

4. Recognize that individuals who have acquired a disability have significant identity issues with which they may need to grapple; they have gone through an extremely personal identity change. This is not currently recognized by the medical system as a critical component of rehabilitation. In addition, research must be conducted to show the impact of this type of counseling or peer support groups, and a health insurance policy addressing adequate reimbursement for this service.

5. The Federal government should track people with disabilities as a separate culture and demographic variable.

6. While students with disabilities are in high school, they need to look at employment needs (or other such transition plans). The *Healthy and Ready to Work* document covers this need. A critical issue is the existence of bias. Transition issues have been overseen by the Department of Education and data are available (e.g., among youth with disabilities who had been out of high school 3 to 5 years, 27% had ever enrolled in postsecondary school, compared with 68% of youth in the general population. The employment rate for youth with disabilities is reported to be 57% compared to 69% in those without disabilities).[2]

7. Identify means to bring constituents, providers, and the public together, either through mediation or via face-to-face meetings, to resolve issues of distrust. There is a lot of distrust at the local level between the different groups and everyone needs to come together to reach solutions. Hiring facilitators would work to implement more objectivity and would better provide an assurance of listening and working side-by-side. However, for American Indian communities, meeting face-to-face would work well at the local level. For instance, the Talking Circle format aims to permit dialogue around issues such as distrust or respect that may be present.

8. We recommend John Bach's article on the approach of using "positive affect" in end-stage ALS[3] be included on quality of life scores. Dr. Bach's work revolves around treatment and management that employ less invasive procedures and interventions.

9. Encourage people with disabilities to enter the journalism, education, and health care professions and provide incentives to students in journalism, education, and health care to pursue education on issues regarding disability.

10. Address discrimination in the selection processes used in certain graduate degree programs (i.e., such as the medical doctorate and education doctorate).

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals?

Our consensus is that adequate mechanisms are not currently in place for tracking progress with this objective. While BRFSS question is currently used, consideration should be given to the limits of BRFSS, including use of the telephone that curtails input from hearing-impaired and mobility-impaired persons. The BRFSS, however, does collect information directly from the person with disability, without using a proxy. Including the new question in the National Health Interview Survey Supplement in 2001 is another good opportunity for data collection; however, there are still difficulties. NHIS collects data about all households and allows information about children, but it also allows proxy responses. An important tracking mechanism might be to compare life satisfaction across cities according to how much they have implemented the ADA. Seattle, Boston, Washington, DC, and Las Vegas are all examples of proactively changing cities.

As indicated at the beginning of the Objective 6.6 report, to the extent that other relevant objectives within this chapter and other *Healthy People* chapters are being met, satisfaction of life should increase overall.

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Objective 6.7: Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles

Objective 6.7a. Reduce the number of adults aged 18-64 years in congregate care facilities by 50%

Objective 6.7b. Reduce to zero the number of children aged 17 years or younger living in congregate care facilities

DEFINITION OF CONGREGATE CARE:
Settings in which children or adults with disabilities live in a group of four or more people with disabilities, in order to receive needed supports and services.

Introduction
Institutions and other forms of congregate care are inconsistent with positive public health policy and practice. They diminish people's opportunities to realize the essential features of human well-being: choice, control, ability to establish and pursue personal goals, family and community interaction, privacy, freedom of association, and the respect of others. The goal, therefore, is to increase the number of people in noncongregate family and community settings where the services and supports they need are made available.

Congregate placements for children should be ended within the decade, if not sooner, consistent with the Statement in Support of Families and Their Children.[1] Permanency planning means that both state and federal policies affirm the principle that "all children, regardless of disability, belong with families and need enduring relationships with adults." Permanency planning also means that state budgets should commit the necessary resources to support children with disabilities and their families.[2,34] Permanency planning for children is initially family-directed; however, the planning process must become increasingly person-directed as a child matures and transitions into adulthood.

Congregate placements for adults should be reduced by 50%. For adults with disabilities presently residing in congregate care settings, state and federal government policies must also affirm the need for community-based alternatives. This should be accomplished by effectively funding community alternatives such as the Medicaid Home and Community Based Services (HCBS) Waiver Program, and other individualized services and supports for persons with disabilities and their families. States should develop mechanisms for conducting person-directed planning for adults with disabilities. To avoid institutionalization, careful family and person-directed planning, and adequate community supports, must be in place for transitioning children with disabilities to adulthood.

I. How *practical* are the targeted goals for implementation by the year 2010?
These objectives are achievable *if and only if* it is the will of federal, state, and local governments, and of the private sector to provide the resources needed, and to structure policies and programs necessary to support families and individuals. There is legislation (though not fully implemented), to support the goal and there have been prior successful efforts towards deinstitutionalization, notably mass closing of large institutions across the US and reduced numbers of children in large care settings.

For persons with developmental disabilities, data on the extent of congregate care utilization are currently available.[3,4] In 1998 in the United States, a total of 92,231 children and adults with developmental disabilities were served in settings for three or fewer persons. This number constituted 22% of the total 416,717 persons served in all out-of-home placements, ranging from state institutions and nursing homes to supported living, personal assistance, and individualized foster homes.

The number of persons served in 1998 in congregate settings for four or more people (324,486) represented a placement prevalence of 121 per 100,000 of the United States general population. Given projected increases in the US general population, a 50% reduction in this number is 54 per 100,000 in 2010.

With regard to persons with physical and mental health conditions, statistics will soon be available from analyses of the "Minimum Data Set" on all nursing home residents. Baseline statistics from this national data set, with individual records for all nursing home residents, will be available early in 2001.

Policies and reimbursement programs must recognize that nonpaid relatives, primarily women, bear the large majority of the responsibility for caregiving in the United States. Family caregivers have major unmet needs that will only increase as the population ages.

There are currently seven states (Alabama, Arizona, Georgia, Maryland, Nevada, New Mexico, and Washington) that have congregate (4+ persons) placement prevalence at or below the national average. These states, and a number of other states in which congregate placement prevalence for children are quite low (i.e., Alaska, Kansas, Maine, New Hampshire, Rhode Island, Vermont, and Wisconsin) should be able to achieve one or both objectives.

II. What are the major *problems* in addressing this objective?

A. Disparities in commitment of states
Wide variations exist among the states in social and policy commitments to develop family support and community services, motivation to change, and information about what can and should be accomplished. States also vary in the levels of resources they commit to family support and community services.

B. Disparities in commitment of community services

Disparities exist in expectations and commitment to community services among different disability groups (and industries), especially care and services for seniors.

C. Disparities in financial resources

We have not made the long-term financial commitment to the long-term care needs of Americans. We do not know what the future needs will be, what it will cost to meet those needs, nor the origin of resources. Recently available data show that an estimated 9.4 million adults, ages 18 and over, need hands-on assistance to carry out either instrumental activities of daily living (IADLs)—chores such as shopping and housework—or for the more basic activities of daily living (ADLs), such as bathing and dressing. Roughly 79% of these people live at home or elsewhere in the community rather than in institutions, and almost half are under 65 years of age.[5] Large numbers of these adults will require increased support as both they and their family caregivers age.

D. Service gaps

1. There are tens of thousands of families and individuals eligible, but still waiting, for support; there are people who have been authorized for support but who are not getting what they are authorized to receive.

2. Given the options, people often seem to feel they do not have the right to request the services they need in the places they want to live.

3. There are significant personnel recruitment/retention difficulties for attendants, personal assistants, in-home support staff, and direct support staff; this limits the capacity to develop and maintain community and family services.

4. There are few, if any, transition programs.

5. There is an imbalance in outflow and influx. When residents leave or relocate, and others are admitted, beds fill as soon as there are vacancies. Waiting lists testify to the need for community support.

E. Governmental policies

1. There is a lack of federal incentives for family and community versus institutional services. Why is the matching rate in Medicaid the same for institutions as for the Medicaid Home and Community Based Services (HCBS) Waiver? Why not use a Federal Medical Assistance Percentage (FMAP) rate incentive like that used with the Children's Health Insurance Program (CHIP)?

2. There is a severe shortage of the affordable, accessible and usable housing that people with disabilities require in order to live in noncongregate arrangements.

3. Government policies and funding do not effectively provide for adequate numbers of self-directed personal assistants. Various policy changes are needed to increase personal assistance.

4. Funding and policy changes are needed to supply assistive technology devices and services.

5. Health care policy still remains oriented to acute care. Too often this means that the accepted outcome is either a cure or death, without the necessary emphasis on meeting the nonmedical needs of people with disabilities. If personal and environmental factors are to be considered as co-equal determinants of disability, then home, work, and community environmental access surveys need to be paid for via some mechanism other than the health care insurance and reimbursement systems.

6. Many state systems for adoption and foster care are often linked to children's protective services, which can lead to "abuse/neglect" stereotyping.

III. Who are the government, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. The federal Health Care Financing Administration (HCFA) and other US Department of Health and Human Services (DHHS) offices, divisions, or programs need to play a proactive role in promoting community services using various existing and potential new planning and family requirements (e.g., plans based on the Olmstead decision of the US Supreme Court).

B. Other partners include federal, state and local Head Start, Early Childhood Intervention, and IDEA (Individuals with Disabilities Education Act) personnel.

C. The Congress and the Administration need to create incentives to move people from congregate care settings to community and family services.

D. Under the leadership of national organizations such as the National Governors Association (NGA), efforts should be undertaken to bring state program agencies (e.g., Medicaid, aging, mental health, developmental disabilities, children and family services, rehabilitation services) into coordinated activity to establish ongoing statistical indicator programs.

E. Centers for Independent Living (CILs), American Disabled for Attendant Programs Today (ADAPT), Family Voices, parents, The Arc (formerly The Association for Retarded Citizens), the American Association for Retired Persons (AARP), and others. These organizations need to work together to promote noncongregate, in-home supports for all groups, and to include *specific* goals such as support for the Medicaid Community Attendant and Support Services Act (MiCASSA). In addition, they must work toward *general* goals such as building a powerful disability constituency in order to influence politics and policies.

F. State Technology Act Projects and the Association of Technology Act Projects (ATAP) are aware of policy and community service barriers to getting the assistive technology needs

met for people with disabilities living in the community. These groups also have their own partnerships.

G.   The US Department of Housing and Urban Development (HUD), and Health Care Financing Administration (HCFA), need to work together to ensure the integration of affordable, accessible and usable housing, and access and use with community supports.

H.   Title V (Children with Special Needs), MCHB (Maternal and Child Health Bureau), and other federal, state and local agencies, other partners such as the Developmental Disabilities (DD) Councils, National Council on Disability, University Affiliated Programs (UAPs), as well as others need to work together on promoting and successfully achieving permanency planning objectives and outcomes, and meeting the person-directed outcomes for adults.

I.   Government agencies, as well as other agencies, need to ensure that people with disabilities are partners with continuous presence in policy-making and evaluation efforts.

J.   Faith-based communities are also needed partners.

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Family support and permanency planning
1.   Adopt permanency-planning principles for children and person-directed planning for adults in legislation, program policies, and procedures.

2.   Some states have developed "road maps" to show how to achieve important community- and family-support objectives (e.g., Michigan worked effectively to have no children residing in congregate care; the Children's Long-term Care Policy Council was created in Texas[6]). We need to highlight state and local progress in important areas and have these leaders provide technical assistance to other states and communities that have further to go.

3.   Provide training, show how to shift the funds, and continue to develop the collective willingness to follow the road map.

4.   State Title V annual reports should be required to report annually on progress in the states regarding permanency-planning objectives. The steps taken in each state to promote permanency-planning principles, including deinstitutionalization, should be reported.

B. Community infrastructure
1.   Reducing and preventing institutionalization and promoting community integration
   a.   Studies on reducing congregate care provide valuable advice on careful deinstitutionalization planning. Funding agencies should study the characteristics,

actions, policies, organizational structure, and financing of leader states and communities and the ways those elements can be replicated.

b. Ensure that dollars are attached to persons, not to beds or programs, such that people with disabilities and those they trust (including family members, neighbors, friends, and service providers) control resources.

c. Government, and persons with disabilities and their allies, must be partners in changing the general social culture so that the general population increasingly views persons with disabilities as full and valued members.

d. The federal government should commit to a policy of people being able to "age in place" such that services come to people rather than making people move to where the services are provided. This policy and principle is established in research literature on aging, and should also benefit people with disabilities as they age.

2. **Effectively assessing needs**
   a. Identify a core set of data descriptive of the resources, programs, and policies affecting long term care and support that would guide the *Healthy People 2010* objectives.

   b. Consider existing state and national data sets.

   c. Identify states that are exemplary in terms of 1) resource allocation, 2) developing programs and policies that promote permanency planning and individual and family support, and 3) having data sets descriptive of these systems of services.

   d. Make recommendations regarding the elements of common data sets and how exemplary states have maintained such data sets.

   e. Determine the possibility for and costs of a national annual reporting system of key indicators of needs (i.e., resources and people).

   f. The nation must develop the long-term financial commitment to funding long-term care, especially because aging baby boomers—both people with disabilities and caregivers—have needs that will dramatically increase in the years ahead.

3. **Providing an appropriate array of housing, services, and supports**
   a. Any individual with a disability, or family that includes a person with a disability, who is eligible for family or community support, is entitled to and should receive those supports within a reasonable period (90 days).

b. Provide wider opportunities for individuals and families to use programs that support community and family living, including, but not limited to:

- Personal care options and other types of personal assistance and supported living
- Supported employment
- In-home support to families, respite care, and specialized day care
- Alternative family arrangements (shared parenting)
- Specialized foster care (supporting the concepts of permanency planning)
- Behavioral support and crisis response
- Accessible, usable, and affordable health care, health promotion, and prevention
- Individual service coordination (independent case management)
- Transition planning and supports
- Assistive technology supports
- Training for foster care

c. Dramatically increase the amount of affordable, accessible and usable housing and assistance with housing modifications and equipment.

d. Work to better understand and enforce accessibility laws consistent with ADA throughout the US.

4. **Financing community services**
   a. Federal and state governments must identify and remove existing disincentives to family and community living (e.g., losing health care coverage when you work a "real" job—i.e., the recently passed Work Incentive Act).

   b. The federal government should establish relative incentives for family and community support as compared with institutional services (i.e., enhanced FMAP rates, as implemented in CHIP).

   c. Federal and state governments must develop commitments and policies to ensure an adequate workforce: 1) adequate pay and benefits, 2) recruitment, and 3) training.

   d. The CDC should work with SSA on the implementation of The Ticket to Work and Work Incentives Improvement Act of 1999, and other incentives to achieve full, productive, integrated community lives.

   e. Federal agencies should coordinate efforts to see that all funding programs, policies, and procedures effectively promote integrated community services and supports that promote maximum use.

   f. Voucher programs should be considered to attach dollars to people, not beds.

V. Are adequate mechanisms in place for tracking *progress* toward meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

A. Individual records on all Medicaid- and Medicare-certified nursing-home residents, now available from the federal HCFA, will track numbers of children and adults with disabilities in nursing facilities.
B. Developmental Disabilities (DD) data sets are available from the University of Minnesota and, as of August 2001, the University of Colorado.
C. There is a need for ongoing measurement and improvement of the extent of accessibility and usability of places where people live and participate in community life.
D. State Title V annual reports should be required to report annually on progress in the states regarding permanency-planning objectives. The steps taken in each state to promote permanency-planning principles, including deinstitutionalization, should be reported.
E. State Medicaid, DD, and agencies including those for mental health, aging, rehabilitation, education, and children and family service, should work together in each state to track progress toward meeting these objectives.
F. Develop the *HP 2010* template for data collection (e.g., age categories, sex, level of schooling, and race/ethnicity)

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Objective 6.8: Eliminate disparities in employment rates between working-aged adults with and without disabilities

Introduction
We strongly support intensifying efforts to move individuals with disabilities toward employment parity with other Americans. Few of the *Healthy People* objectives hold greater promise for moving people with disabilities toward participation in the national economy and the mainstream of American life than Objective 6.8.

Having said that, however, we strongly recommend that Objective 6.8 be construed more broadly in order to give an accurate accounting of the critical nature of unemployment, impoverishment, and dependency among people with disabilities in general, and among individuals with more significant disabilities in particular. Three preliminary issues need to be addressed prior to discussing our specific recommendations. These preliminary issues include: 1) how the baseline measure of employment rates for Objective 6.8 has been calculated; 2) how the baseline measure is currently defined in Objective 6.8; and 3) how the baseline measure *should* be defined in Objective 6.8.

The Baseline Employment Rate of Objective 6.8
The overall goal of Objective 6.8 is an employment rate of 82 % for persons with disabilities. The baseline measure is calculated using data from the US Bureau of the Census report *Americans with Disabilities: 1994-95.*[1] The baseline employment rate for persons with disabilities contained in Objective 6.8 is 52%. This is the actual percentage of all persons with disabilities who are employed.

The Baseline Definition of Employment Rates
As noted above, achieving the overall goal of Objective 6.8 is based on 82% of persons with disabilities being employed, as defined under SIPP. Employment is defined broadly under the SIPP data source to include full, part-time, temporary, or any work that earned money during a 4-month time period. We strongly urge that SIPP data be used to examine the rates of employment for people with and without disabilities by reporting on the three most critical elements of employment: 1) employment status (i.e., full-time or part-time, ongoing or intermittent employment, etc.); 2) income (i.e., wages earned over the SIPP's 4-month reporting period, annualized); and 3) benefits (e.g., health care, retirement, sick leave, vacation). Because people with disabilities, and particularly those with significant disabilities, are also disproportionally employed in part-time, low-wage, and no-benefit jobs, SIPP data that only report on the overall percentages of people employed in any capacity over the previous 4 months distorts any measure of meaningful comparison between those with and without disabilities in regard to the fundamental goal of *Healthy People 2010*—that is, to maximize the quality and years of healthy life for persons with disabilities.

A Modified Baseline Measure for Objective 6.8
In addition to an expansive definition of employment (rates, income, and benefit levels), it will remain crucial to ensure that data in these three categories are reported at all times by differentiating between persons with less and more involved limitations. It is important to

acknowledge and report the substantial differences in employment between these two groups because of the far more significant challenges individuals with significant disabilities face in moving toward meaningful parity in employment with their nondisabled co-workers.

I. How *practical* is the targeted objective of eliminating employment disparities in employment rates between working-aged adults with and without disabilities for implementation by the year 2010?

Despite a history of excluding people with disabilities from the workforce, we believe the objective is practical based on several factors. The target is an employment rate of 82% as opposed to a target of full employment. Employment is defined broadly under the national data source (SIPP data) to include full, part-time, temporary, or any work that earned money during a 4-month time period. The baseline employment rate contained in *HP 2010* is set at 52%. Given that the baseline measure uses a broad definition of employment (and that the population of persons with nonsignificant disabilities is significantly larger than that of individuals with significant disabilities), the goal is more readily achievable since a significant percentage of persons with disabilities meet the employed criterion already.

II. What are the major *problems* in addressing this objective?

Barriers to reaching this objective have been grouped into three categories, including problems emerging from employers, systemic problems, and specific problems facing persons with disabilities.

A. Employers
1. Employers view people with disabilities as a homogenous category.
2. Significant numbers of employers view people with disabilities negatively and may use evidence of disability from applications or visual impressions as a way to reject candidates.
3. There is a relative lack of economic incentives to employers to hire people with disabilities (notwithstanding some incentives that may exist for tax credits and practicing good will, and government mandates to hire more people with disabilities).
4. Higher rates of health care and insurance utilization by people with disabilities create disincentives for employers (especially small business entities) to hire persons with disabilities.
5. Many work, physical, and communication environments are inaccessible or unusable for persons with disabilities.

B. Systemic problems
1. Employment issues for people with significant disabilities are more complex than those for persons with nonsignificant disabilities. There is a disproportionate number of people with significant disabilities who are unemployed.
2. Job re-entry after adult-aged onset of disability can be more complex than job transitions by persons who have had chronic conditions since childhood.

3. Transition planning for youth to adult employment is often a low programmatic priority and underfunded.
4. Lack of knowledge about disability issues on the part of both workers' compensation administrators and human resource personnel is problematic.
5. People with disabilities are diverted from work to welfare by workers' compensation statutes and by employers who are downsizing.
6. A number of economic issues suppress employment opportunities. That is, people with disabilities are laid off in disproportionate numbers in economic downturns. This is because they often have had less work experience due to employment discrimination, and that leads to being subjects of the "last hired, first fired" phenomenon. People with disabilities may also find themselves in marginalized jobs that are eliminated in economic downturns.
7. Vocational rehabilitation programs (governmental and nongovernmental) can be ineffective, in particular when they rely on part-time and sheltered employment as successful employment outcomes, steer persons toward dead-end jobs, or address employment as a secondary goal.
8. There is a lack of fit between many education and training programs for people with disabilities and the nature of 21st century work generally.
9. Appropriate assistive technology (AT) is not routinely a part of:
   a. K-12 educational programs such that it would better prepare students for college or work;
   b. transition planning to answer the question: "What work could students do if they had AT?";
   c. independent living, so that people with disabilities can get ready to go to work; and
   d. employment as a reasonable accommodation.

C. Specific problems facing people with disabilities

Many problems facing people with disabilities stem from systemic sources, as well. There are ongoing efforts from many agencies and organizations, including NCD, HCFA, DOL, and SSA, to address these problems; examples of specific programs are those that ensure employee maintenance of health benefits and coverage, and the grants originating through the *Ticket to Work and Work Incentives Improvement Act of 1999*. These efforts notwithstanding, some problems justify mentioning here:
1. Many people with disabilities lack basic educational opportunities.
2. Many persons with disabilities who have access to and use of educational programs receive skills and training that do not match available jobs.
3. People with disabilities often have a lower income than others because of part-time, low pay-scale jobs.
4. A person with disabilities in the same job as someone without a disability may be paid less.
5. There is inadequate support to persons with disabilities alleging employment discrimination under ADA.
6. Persons with disabilities also face discrimination based on minority and gender status.
7. Many persons with disabilities fear losing their health insurance if they return to employment after a stretch of time.

8. Significant percentages of persons with disabilities are at risk for poor health as a result of exclusion from health-maintenance programs and other factors.
9. Many employment opportunities lack health-care or other health-support services.
10. People with disabilities may lack the social skills to hold or be successful at jobs.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be partners in implementing this objective?

Many organizations and agencies could take an active role in helping achieve this objective.

A. *At the federal level,* the Departments of Labor, Education (OSERS; NIDRR), Health and Human Services, and Transportation, Justice; NCD; the Equal Opportunity Commission (EOC); SSA, SBA, VA, Indian Health Services (IHS), Bureau of Indian Affairs (BIA), and Congress (including staffers).

B. *In the individual states*, partners include the Vocational Rehabilitation (VR), Disability or Human Services, Medicaid, and the various health departments and divisions.

C. *In nongovernmental organizations*, CARF, special education technology (SET), the National Association of State and Territorial Health Officers (NASTHO), National Association of City and County Health Officers (NACCHO), National Association of State Health Programs, National Education Association (NEA), AARP, American Management Association, Chambers of Commerce, American Academy of Actuaries, the Council of State Administrators of Vocational Rehabilitation (CSAVR), and State Technology Act Projects and the Association of Technology Act Projects (ATAP).

D. *Consumer and family organizations* include The Arc, People First, and CCD, APRIL, and NCIL.

E. *Others partners* would be the Welfare to Work System (federal and state).

F. *Foundations* such as Robert Wood Johnson, Pew Charitable Trust, Kaiser Permanente Community Foundation, and Henry K. Kaiser Family Foundation.

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet the objective?

A number of task forces and blue ribbon panels[2] have examined mechanisms for increasing employment opportunities for persons with disabilities. Each of those reports and recommendations should be reviewed for applicability to Objective 6.8. Opportunities that could help meet this objective as identified by the work group have been divided into four categories: employers, persons with disabilities, federal initiatives, and the insurance sector.

A. Employers
1. Provide to employers educational programs that range from an introduction about disability to programs on how to provide reasonable accommodations (e.g., via brochures, American Management Association courses, Certified Employee Benefits Specialist courses).
2. Provide economic incentives to businesses (i.e., tax credits, to encourage them to hire persons with disabilities).
3. Establish a stronger mandate to comply with ADA.

B. People with disabilities
1. Increase vocational, secondary and post-secondary educational opportunities through an incentive program for both people with disabilities and educational or training institutions.
2. Restructure vocational rehabilitation programs to emphasize preparing individuals for 21st century jobs.
3. Increase substantial gainful employment allowance (SGA) and allow accumulation of wealth/savings to the poverty income level; SGA is a key phrase in SSA legislation that limits what people who are on social security disability income (SSDI) and social security insurance (SSI) can earn before being removed from SSA programs.
4. Eliminate disincentives to work by maintaining Medicaid/Medicare coverage under employment.
5. Obtain educational opportunities and support from ADA enforcement.
6. Increase access to and use of transportation.
7. Revisit the concept of health care for persons with disabilities as a program of equity.

C. Federal government
1. Perform surveillance: Use data to monitor 1) the employment, income, and benefit levels of people with disabilities, including those with significant disabilities who have higher risks for unemployment and underemployment (such as persons with mental illness); and 2) disability and employment by race, ethnicity, gender, and education.
2. Increase enforcement of ADA.
3. Develop a support system during difficult economic times; i.e., a system to protect people with disabilities from job loss when the economy contracts.
4. Teach job and social skills as part of education programs.

D. Insurance sector
1. Develop model state legislation through the National Association of Insurance Commissioners (NAIC).
2. Integrate health benefits and carve-outs with workers' compensation, SSDI, and SSI.
3. Expand the notion of restorative therapy to the fuller concept of maintenance therapy (as a medical necessity).
4. Provide small-group reinsurance for high-risk individual employees and the self-employed. (Note: Reinsurance is a practice common in the workers' compensation field. It is, in effect, the insurance of insurance, whereby one insurance company, which has risks that it deems too large to carry, insures that risk with another company).

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

In order to track progress, comparisons need to be made between SIPP employment, income, and benefit level data for people without disabilities and persons with significant and nonsignificant disabilities, including those with significant disabilities who have higher risks for unemployment (such as persons with mental illness). Comparisons also need to be made by race, ethnicity, gender, and education. In addition, SIPP data should be compared to BRFSS data on employment, income, and benefit level between people without disabilities and persons with significant and nonsignificant disabilities, and by race, ethnicity, gender, and education (see Objective 6.1).

Other federal surveys, such as the Bureau of the Census Current Population Survey (CPS), conducted in March 2001, may ask the right questions, but the sampling process results in statistically insignificant numbers of people who have moderate and significant disabilities. The small numbers preclude decision-makers from being able to analyze employment rates at levels other than nationwide. More meaningful analyses could be drawn in the data that are collected and reported at statewide or even major metropolitan statistical area (MSA) levels. BRFSS may be a useful vehicle in this enterprise in that it can be analyzed by zip code.

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Objective 6.9: Increase the proportion of children and youth with disabilities who spend at least 80% of their time in regular education programs.

Target = 60%
Current baseline = 45% (of children 6-21 years)

Introduction
As written, this objective targets the placement of children with disabilities in regular education. It does not address the broader sense of inclusion (incorporating inclusion in other aspects of school life) applied elsewhere in *HP 2010* or the *ICF*.

Given the wording and the use of Office of Special Education and Rehabilitative Services' (OSERS) data to establish baseline and target figures, it is clear that the population to which this objective refers is the one defined under the Individuals with Disabilities Education Act's (IDEA) definition of a child with a disability as is represented by IDEA's thirteen eligibility categories. It is important to keep in mind that this does not represent *all* children with disabilities participating in regular education. For example, the objective does not include children with chronic health conditions who have section 504 plans, or other children with limiting conditions who otherwise do not require (or are not receiving) special education.

I. How *practical* are the targeted objectives for implementation by the year 2010?

This goal reflects the current OSERS goal for 60% of students served under IDEA to be served in the future in the regular education classroom at least 80% of the time. We view the goal as *attainable only if there are appropriate supports and services.* This proviso is important to ensure that participation in regular education is understood to mean more than merely "physical" inclusion in the same classroom. The goal is not only attainable, but also important, given (1) the history of exclusion of students with disabilities and (2) recent legislation that mandates access for children with disabilities into the general education curriculum.

Additional important issues were raised related to this target. They are:
1. Inclusion must take place and be evaluated in the context of choice. That is, under the current circumstances, is inclusion a family's choice for their child? (Choice here signifies true choice among a full range of appropriate options).

2. Is it presumptuous to assume that 60% of families want and believe that 80% participation is the most appropriate option for their child?

II. What are the major _problems_ in addressing this objective?

A. Attainment of the goal must be examined by factoring in appropriate supports and services, not just placement. However, data on what actually is provided have been difficult to obtain. Data on this issue will be available from the Special Education Elementary Longitudinal Study (SEELS) by January 2002, and the National Longitudinal Transition Study-2 (NLTS-2) by January 2003.

B. If families do not consider the local, regular education program as a quality environment for all students, what incentive do families have to pursue inclusion of their child with special education needs? Families may perceive that in some circumstances alternative settings provide better overall quality for their child. This choice should be acknowledged and respected.

C. Under IDEA, schools have the primary responsibility, and are operating within a clear and specific mandate, to provide a free, appropriate, public education to students with disabilities. However, when other agencies do not meet their responsibilities and agreements as a cost-cutting strategy, for instance (e.g., health care and services from social service agencies), schools must pick up the responsibilities for those services. Although families and communities have options for due-process procedures with schools, there is little they can do to address the loss of services from outside agencies. Recently many schools have looked to bill Medicaid for some of the health-related services they have been providing (e.g., physical, occupational or speech therapy; accessible transportation). There has been considerable confusion about the conditions under which such billing is appropriate. To address these problems, HCFA should soon publish a guide to the appropriate items for which to bill Medicaid. It applies that states will have the prerogative to bill Medicaid if the services are in the student's Individualized Education Program (IEP) and may only do so for students who are Medicaid-eligible.

D. Being able to participate successfully (i.e., learn) in general education classrooms requires coordination of needed services within the educational system and across other systems.

E. Lack of service integration in and out of school is a significant barrier for inclusion. It is overly complicated for families to have to manage this coordination on their own. State interagency agreements are supposed to clarify responsibilities with regard to the coordination of services for students with disabilities, but often they do not do so consistently.

F. Among states and among urban, suburban and rural systems, there is a wide range in philosophy, funding, approach, implementation and actual percentages of students in inclusive settings. There are also important regional differences in attitudes and values (e.g., on the East Coast a private placement has prestige).

G. There are great differences from state to state in how funds are linked to specific students (versus being made available to the system as a whole to support special education needs) and how special education costs are supported. Some analyses have suggested that the federal government has not met its obligation for fully funding IDEA, placing undue burden on state education agencies and local school districts. However, the procedural differences across states in how funds are calculated and distributed make it difficult to sort this out. It is clear that in many states and school districts there are funding disincentives for inclusion. One example of this is that more reimbursement is often provided for an outside or segregated placement than for supports within the regular education program. Many states and school districts may not understand new options for supporting inclusion and have not implemented the necessary changes in their systems.

H. Good cost estimates for including particular students, and which could serve as guidelines for school districts or others involved in implementing IDEA, do not exist. The Office of Special Education Programs (OSEP) is currently conducting a financing study that addresses some of these issues.

I. There is a tendency to consider only the short-term costs of supports rather than the long-term benefits. Those benefits would come from the provision of appropriate supports for inclusion. In other words, instead of providing merely adequate supports now, look at how offering more complete supports *now* might prevent *later* difficulties. Full consideration of costs must encompass all areas. An example of this is considering the more immediate cost of education services and technology versus taking into account the long-term benefits of health and productivity. Overhead should be measured as a separate cost since it is not as easily recognized as the concrete costs of hiring aides, for instance; this can make a big difference in implementation efforts.

J. There is a lack of appropriately qualified personnel at multiple levels, from aides to teachers who were trained for separate programs. Low salary levels relative to the required years of educational preparation and level of responsibility are a problem everywhere.

K. There are attitudinal barriers. Educators and administrators often believe that "self-contained" is still the best approach to educating students with disabilities.

L. Many parents are not well informed about the intent of LRE (least restrictive environment) and inclusion, or the processes of IDEA. The group of parents whose children have been served under Part C of IDEA are more sophisticated and have higher expectations for what should be provided and what choices can help them when their children transition to elementary school. However, parents whose children are identified later do not have this information. The kinds of procedures established to implement IDEA often presuppose that parents who have prior special program involvement are those who can more comfortably approach teachers and administrators.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

"Partners" refers to our approaching others as well as others coming to us, and that we need to form a "we." In other words, almost any entity that deals with children would be a partner. However, some of the more apparent ones are listed here

A. Government/policy groups
  1. Interagency Coordinating Councils (ICC), for IDEA Part C
  2. MCHB and Title V programs
  3. SSA
  4. DOE
  5. NGA
  6. Council of Chief State School Officers (CCSSO)
  7. National Conference of State Legislators (NCSL)
  8. CSAVR
  9. Substance Abuse and Mental Health Services Administration (SAMSHA)
  10. ATAP

B. Education
  1. National Education Association (NEA)
  2. American Federation of Teachers (AFT)
  3. Association for Supervision and Curriculum Development (ASCD)
  4. Council of Chief State School Officers (CCSSO)
  5. National Association of Bilingual Education (NABE)
  6. American Association of School Administrators (AASA)
  7. Council of Administrators of Special Education (CASE)
  8. Council of Great City Schools (CGCS)
  9. National Alliance of Black School Educators (NABSE)
  10. National Association of Elementary School Principals (NAESP)
  11. National Association of Secondary School Principals (NASSP)
  12. National Indian Education Association (NIEA)
  13. Association for Career and Technical Education (ACTE)
  14. National School Board Association (NSBA)
  15. Quality Education for Minorities (QEM) Network
  16. Academy for Educational Development (AED)
  17. Council for Exceptional Children (CEC)
  18. National Association of State Directors of Special Education (NASDSE)

C. Health service professionals
  1. American Academy of Pediatrics (AAP)
  2. National Association of School Psychologists (NASP)
  3. National Association of School Nurses (NASN)
  4. American Occupational Therapy Association (AOTA)
  5. American Physical Therapy Association (APTA)
  6. American Speech-Language Hearing Association (ASHA)

7. American Public Health Association (APHA)
8. American Psychological Association (APA)

D. Advocacy and parent groups
1. Centers for Independent Living (CILs)
2. Coalition for Citizens with Disabilities (CCD)
3. American Association of People with Disabilities (AAPD)
4. National Council on Disability (NCD)
5. March of Dimes
6. The Arc
7. Parent Advocacy Coalition for Educational Rights (PACER)
8. National Council on Independent Living (NCIL)
9. Alexander Graham Bell Association for the Deaf and Hard of Hearing
10. The Federation of Families for Children's Mental Health
11. Center for Law and Education
12. National Down Syndrome Congress
13. Parent Training and Information Centers (PTI)
14. Parent-teachers associations (PTA) and parent-teacher organizations (PTO)
15. Parent-to-parent organizations
16. Grassroots Consortium
17. State and local parent groups funded by SAMSHA (mental health)
18. Family Voices
19. Fiesta Educativa
20. National Association for Parents of the Visually Impaired

E. Community/social services
1. Juvenile justice system
2. Public health agencies
3. National Indian Child Welfare Association

F. Corporate entities
1. Managed care organizations
2. Pharmaceutical companies
4. Software technology companies (e.g., Microsoft)
5. National Ad Council
6. Public relations firms

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Effort toward this objective is already mandated under IDEA.

B. Encourage DOE to collect appropriate funding data. In states, eliminate funding disincentives to inclusion.

C. Examine the use of Medicaid funding. Look at Medicaid policy and how it impacts service delivery under IDEA when these funds are tapped. That is, local education authorities can bill Medicaid for some related services (e.g., occupational therapy, physical therapy) provided to children in special education. However, because Medicaid is a medical/health coverage program that typically funds "medically necessary" services, those services provided under IDEA are not determined on the basis of "medical necessity" but on the basis of supports needed to enable effective participation in the educational program.

D. Examine state health professional practice acts that impose restrictions on the ability to delegate or deliver services in flexible ways. That is, certain health-related supports require administration by specific professionals, for instance, a registered nurse (RN). If there is no such person on site, the activity cannot be delegated to someone else, even following appropriate training, so a child may be restricted from placement in that setting. Training to understand the multiple systems involved in services—policies, regulations, advocacy, and training in how to function in a consultative role—is also needed.

E. Incorporate functional life skills and career skills in the general education curriculum. Assess high school curricula and their content (e.g., many programs focus exclusively on academic skills and do not provide a regular education curriculum oriented toward life skills needed for productivity and independent living.)

F. Provide adequate and appropriate training for teachers, administrators, and other service providers to support inclusive practices.

G. Examine the use of personal care assistance (PCA) models in the school setting; for example, make PCA training a part of vocational education.

H. Examine the impact of zero-tolerance policies (regarding school safety from violence) on inclusion and the ability to meet special health needs (e.g., restrictions on students having access to respiratory inhalers, or lancets for diabetes blood-glucose testing)

I. Recommend that all schools have one school nurse on campus to care for all students and to better ensure inclusion of students with health conditions.

J. Examine mental health supports in schools. For example, support personnel, such as school psychologists, are often involved in assessment with little time for consultation. Intensity/use of pre-referral mental health interventions varies significantly across states. Mental health services can be successfully incorporated into school health clinics. (Collaborate and integrate with efforts for achieving *HP 2010* Objective 6.2: *Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed*.)

K. Synthesize and disseminate information on effective inclusion practices. Information should be tailored to meet particular audience needs (i.e., parents, teachers, etc.). Look at

data from states that have already achieved, or have come close to achieving, this objective in order to identify those programs that can serve as models. Describe how successful model programs accomplished objectives, and disseminate findings in the most accessible and usable format possible.

L. For educators and service providers, support the access to and use of assistive technology that is designed to 1) increase efficiency and effectiveness by reducing paperwork and 2) increase access to relevant student information while assuring confidentiality.

M. Provide training and access to technology for students and their educational team members (teachers, assistants, related service providers) to maximize the use of technology. Note: Funding mechanisms often only fund equipment and not training of students and personnel in the effective use of the technology.

N. Support effective interdisciplinary training for all educators. Participants in IDEA should understand how their roles intersect and combine to support the ultimate objectives. Support training of stakeholders and other educators to understand the multiple systems involved in providing educational services— policies, regulations, as well as advocacy and training in how to function in a consultative role.

O. Advocate for and provide training on universal design for textbooks and on architectural designs for new schools.

P. Focus on technology that might benefit other students, not just those with disabilities. For example, provide texts in alternative formats or texts that are readily adapted to different levels, needs, and learning styles. Develop and provide teacher guides for how to use the same text to address different needs and in varying presentation modes. Help create a mindset that focuses on what would help everybody, not just concentrating on tailoring situations and devices to the students with disabilities.

Q. Collaborate and integrate with efforts for *HP 2010* Objective 6.11: *Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.*

R. Provide public awareness activities to emphasize the benefits of inclusion not only to special education students, but also to the larger public; for example, establish disability study units for all grade levels, K-12.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

A. The current system provides adequate measures for tracking progress towards tracking this objective. However, there are data available:
1. *By age:* Inclusion definition and issues for ages 18-21 are different; 18-21 reflects the usual age after high school graduation for most youth. Regular

education programs in traditional high schools may not offer much for this age group, which then makes inclusion difficult.

2. *By disability category*: Progress is being made in inclusion for all groups of students. Some groups, such as students with speech/language impairments, already surpass the 60% target.

3. *By state*: Some states may be meeting or exceeding the objective now; they might serve as models.

As has been mentioned, there is limited information on related aspects of this objective (see section II, A and H).

B. Recognize that IDEA reporting data does not capture all students with disabilities as defined by other measures. It does not include students with Section 504 plans. In this context, "students with disabilities" only includes those who receive special *education* services under IDEA.

C. Track dropout rates for students with disabilities. As more states implement "high stakes" testing for graduation—often with inadequate supports or alternatives for students with disabilities—dropout rates may increase as students decide the effort to "stay the course" is too difficult. Increases in inclusive participation rates must not be achieved by increased dropout rates.

D. Gather data about specific services and supports to encourage inclusion; OSERS longitudinal studies may include these data.

E. Make efforts to see whether data related to students with disabilities are compatible across studies; for example, do Medicaid expenditure studies refer to school supports for students with disabilities?

F. Check the adequacy of the audit system for OSERS data collection and reporting at the local level. Are currently reported participation rates accurate?

G. Look for different ways to measure inclusion by using a broader definition (e.g., inclusion in extracurricular and health-related activities).

H. Emphasize and support the idea of special education as a right and a service, not a program.

VI. Conclusion

For the future, look at alternative ways of setting this objective and measuring success rather than simply using the proportion of the total group and the proportion of overall time spent in regular education. Ultimately, it is the adequacy of supports and services that is most closely linked to health and well-being, not the placement of children. Schools (and advocates) must keep in mind factors such as safety, friendships, and adequately trained personnel.

Families must have informed choice in school and classroom placement for their children with disabilities. They will only have true choice across the continuum if there are adequate supports for including students with disability in regular classrooms. As students with disability mature, they must also have the right to make informed choices.

Objective 6.10: (Developmental) Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities

Introduction

Achievement of fully inclusive health, wellness, and treatment programs in accessible facilities will resolve many issues of health-related prevention and intervention. This objective is feasible through the collaboration of numerous agencies. Accomplishing the activities in this objective will provide an opportunity for today's advocates across lifestyles, disciplines, and law-making/law-surveillance agencies to build upon the civil rights work of prior decades. In addition, the science associated with the objective will allow stronger data and policy to develop.

I. How *practical* are the targeted goals for implementation by the year 2010?

Given that there are no data associated with this developmental objective, we examined for their practicality the two overall goals of *HP 2010* Chapter 6. We consider these goals— *Maximizing the Quality and Years* of *Healthy Life for Persons with Disabilities*, and 2) *Eliminating Disparities Between People with and without Disabilities*—to be practical.

We can progress toward achieving these goals and still achieve the objective. For 10 years ADA has provided standards and guidelines. As the most pervasive disability rights law, it has provided the power to move us toward full inclusion; however, we still have a long way to go toward ADA's application in specific health and wellness environments.

The feasibility of this project is enhanced by the five funded *ICF* projects, which will have established initial data as well as tools and mechanisms, in the areas of: 1) recreation and fitness, 2) tools for communication, 3) community checklists through assessments of Centers for Independent Living (CIL model states), 4) schools and other environments for children, and 5) community access and use.

Therefore, although it is unlikely that "eliminating" disparities or even "maximizing" quality and years of healthy life are realistically achievable in full, these are worthy targets toward which maximal effort should be exerted. Once valid, instruments are developed to measure accessibility of the environment, including health and wellness programs and facilities, it will be possible by 2003-2004 to establish baseline data and develop a target to be achieved by 2010.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch have concluded an agreement by which data to measure this objective will be included in the NHIS supplement during 2002.

II. What are the major *problems* in addressing this objective?
The following problems exist for addressing this objective.

A. Definitions
1. There is an inconsistent use of "disability" definitions and categories across systems. (See Objective 6.1)
2. There are unclear criteria for the construct; that is, "full access" is not clearly defined as it applies to that which pertains to means of communication, entrance and use of facilities, and multiple formats of information for those with physical, sensory or cognitive disabilities. Examples of multiple formats would include Braille, large print, screen readers (for Internet information), voice-activated devices for persons who cannot read, and accommodations for persons with hearing impairments (such as print handouts for verbal presentations).
3. The meaning of "inclusive" wellness treatment programs and facilities is unclear.

B. Dissemination and monitoring of best-practice health and wellness, and treatment, information (programs and facilities) is the means by which positive change will occur.
1. The objective is extremely broad in scope as it applies to:
   a. acute-care and long-term issues,
   b. primary and secondary conditions,
   c. health maintenance issues, and
   d. the impact of impairment upon activities and/or participation.
2. Identification of similar projects and creation of collaborative networks will be a substantive undertaking. Health, wellness and treatment programs cut across various disciplines and professional groups; this may make it difficult to collect consistent data across domains (rehabilitation, fitness, etc.)

C. Criteria development
1. What to measure; how and when?
2. Optimal data should include: a) End-user data across a broad variety of activity and participation limitations; and b) on-site facility assessment in conjunction with self-report.

D. Data collection and management
1. A large number of unrelated data tracking systems exist for disparity issues
2. A broad scope of entities (agencies, professions, end-user groups, policy-making groups, etc.) are involved.
3. Relevance of potential data markers must be verified by end-users.

E. Evolving research methodology
Valid and standardized instruments to measure community accessibility will probably not be completed until 2003 (five *ICF* projects).

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

Because the breadth of this project calls for elimination of disparities (between people without and with disabilities) across a broad range of programs and facilities, a key activity will be to identify those stakeholder groups who are already invested in some aspect of implementing this activity and achieving this objective.

There are tiers in this implementation. They are:
- Because the *ICF* Objective 6.12 project has the charge to develop tools for data collection, it is suggested that those who are invested in this activity (such as those connected with *HP 2010* Objectives 6.1 and 6.10) review the *ICF* tools and work collaboratively with them.
- A small appointed group should verify that the collaborators include end-users, policy-makers, service providers, and researchers. A preliminary suggested list follows.

A. Disability/advocacy organizations
This list includes the NCIL, AARP, American Society on Aging and other "aging" interest groups, Access Board, Robert Wood Johnson Foundation (RWJF), Gray Panthers, Consortium for Citizens with Disabilities (CCD) Health and Wellness Task Force, and health and rehabilitation professional organizations such as the Society of Public Health Educators (SOPHE), AOTA, APTA, ASHA, American Dental Association (ADA), American Medical Association (AMA), Association of American Medical Colleges (AAMC), Association of Assistive Technology Act Projects, Independent Living Research Utilization at The Institute for Rehabilitation Research, NCPAD Disability and Business Technical Assistance Centers (DBTACS), and national disease/specialty associations such as the American Heart Association, American Cancer Society, American Lung Association, and American Psychological Association (APA).

B. Designers/builders
American Institute of Architects (AIA), American Planning Association, American Builders Association, national and state departments of transportation, and those involved with universal design.

C. Governmental agencies
This category includes the US Architectural Access Board, CDC, National Association of City and County Health Officials (NACCHO), NIDRR, NCD, OSERS, and state and local public health agencies.

D. Health and wellness organizations
National Therapeutic Recreation Society (NTRS), International Association of Fitness Professionals (IAFP), American Council on Exercise, National Governors' Council on Physical Fitness, President's Council on Physical Fitness and Sports.

IV. What are initial *programs*, current or envisioned, and/or *policies*, that could help meet this objective.

A. Data
1. Integrate with current data-collection activities and foster inclusion of the disability-identifier questions (*ICF* projects, BRFSS, National Immunization Survey [NIS], Youth Risk Behavior Survey [YRBS], NCHS). On appropriate questions, expand data to determine "why" disparity exists.

2. Establish additional mechanisms to increase the visibility of disparity data.

B. Standards
1. Strengthen the information center or clearinghouse for Standards and Guidelines of Accessibility of Facilities and Programs (National Center on Physical Activity and Disability).

2. Establish standards, guidelines, and policies for a "Code of inclusion" or a "Code of accessibility/usability."

3. Raise awareness on the demand side; provide "how-to" information.

4. Promote development of programs and facilities for alternate-format access to information about health and wellness opportunities.

C. Public finances
1. Convince HCFA to include functional assessment on patient encounter forms.

2. Expand Medicaid funding for health and wellness.

3. Encourage health maintenance organization (HMOs) to finance health and wellness programs.

D. Incentives
1. Establish incentives for the private sector to establish "health risk assessments" for people with disabilities.

2. Search and identify other options for health and wellness funding (e.g., in the private sector).

3. Create incentives for programs and facilities that meet ADA compliance (e.g., tax incentives for inclusionary health and wellness programs; wrap-around federal credits).

4. Establish a priority for using trust monies (e.g., the tobacco industry class-action litigation settlement funds, DUI trust funds, Blue Cross/Blue Shield for-profit status, etc.)

E. Funding
Encourage funding agencies to support initiatives that promote training programs for caregivers (e.g., personal assistants, home health aides) and professionals (e.g., personal fitness trainers) and that support linkages with health and wellness programs (e.g., access to a YMCA).

F. Education and training
1. Provide disability-related professional certification for both facilities and individuals.

2. Provide education regarding the guidelines.

3. Include criteria for accreditation standards for various professional groups (all aspects of professions related to health, wellness, etc.)

V. Are adequate mechanisms in place for tracking *progress* toward meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?
Although there are a number of tracking systems in place, they are inadequate. Suggestions for improving these systems are to:

A. Expand long-term disparity data (areas not covered in current efforts; one example is shelters for battered disabled women; the nation's 2,000-plus shelters are routinely inaccessible to people with disabilities mainly due to the lack of assistance with activities of daily living [ADLs]).
B. Partner with NHIS and add questions about facilities. Address the over-sampling procedure for people with disabilities and analyze the *reason* for the disparity.
C. Develop a facility-accessibility and -usability assessment program.
D. Develop a program-access and program-usability user survey. A program-access user survey conducted by the Center for Research on Women with Disabilities found that many battered women's programs do provide several disability-related services; most claimed to be wheelchair accessible, but often only to access the administration/intake building. Some programs had wheelchair-accessible emergency shelter facilities.
E. Use Health Plan Employer Data and Information Set (HEDIS) data to rank health insurance programs, including accessibility of facilities and programs as a measure.

VI. Recommendations
The term "treatment" is often used in order to be politically correct. We recommend identifying wherever and whenever that is the case.
A. Although we are moving toward using more autonomous terms, such as "end-user" and "consumer," there are appropriate times to consider a person as a "patient." As we agreed upon this in a colloquial way, whenever a person is wearing an open-backed hospital gown, he/she can be referred to as a "patient." In that particular circumstance, it is probably okay to consider the intervention done at this time as "treatment." However, when that person is finished with the acute phase of his/her illness or condition, he/she is

not to be seen exclusively as a patient, but in a whole-life, larger context; that is, as a person (or consumer or end-user) who has a limitation in activity and/or participation.

B. The term "treatment" has a specific meaning in medicine and should only be used in a medical context. A person receiving medical care would be in a "treatment" program; a person receiving health promotion and wellness advice or counsel would be receiving everything else. Treatment is ordinarily used as synonymous with "curing" and refers to an illness, injury, or disease; health promotion follows the treatment phase.

Objective 6.11: Assistive Technology: (Developmental) Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed

Introduction

Although the official objective cannot be changed, we propose the following language modification in Objective 6.11: Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed *to participate in home, school, play, work or community activities.* This will strengthen the overall participation of individuals in their personal activities and in society.

Assumptions

1. Assistive technology (AT) signifies "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" as defined in the Assistive Technology Act of 1998.[*] This includes devices and related services and is not limited to Medicare's current definition of durable medical equipment. Assistive technology, therefore, includes mass-market products with universal design features, and is not restricted to "special" equipment used only by people with disabilities.

2. Assistive technology can be used to increase independence and reduce health disparities. It is an important element in achieving the goals of *HP 2010*. As such, AT utilization should not be used as an indicator of negative health status in measurement and data collection for any objective. It is counterproductive to use functional measures that discriminate against the use of assistive technology (as pointed out in *HP 2010* Objective 6.4).

3. Assistive technology is not a substitute for other types of support services, but an adjunct to them.

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[*] Definitions from the Assistive Technology Act of 1998, PL 105-394: (1) The term "assistive technology device" means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." (2) The term "assistive technology service" means any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device. Such a term includes: (A) the evaluation of the needs of an individual with a disability, including a functional evaluation of the individual in the individual's customary environment; (B) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by individuals with disabilities; (C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing of assistive technology devices; (D) coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs; (E) training or technical assistance for an individual with disabilities, or, where appropriate, the family of an individual with disabilities; and (F) training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of individuals with disabilities.

4. Assistive technology generally refers to technology used by an individual. It is important to keep in mind the differences between "public/environmental technology" and "personal technology," and the interactive relationship between them. There are things an individual can do to effect change (e.g., buy and use more personal technology, develop additional skills, use personal assistance) and things that communities and businesses can do; that is, make public and commercial space accessible to and usable by all.

I. How *practical* are the targeted objectives for implementation by the year 2010?
This objective is termed "developmental" because there are currently no national surveillance data to support its inclusion as a data-driven objective. When data are available, there will be more clarity about setting a target. The objective is very important, but data are needed to move forward.

II. What are the major *problems* in addressing this objective?
We have identified six (6) major obstacles with regard to personal assistive technology (AT). They include the following.
1. *A lack of appropriate data*; for example: prevalence of AT use, AT use over time, and access to and use of AT; also, the lack of data as it applies to emerging disability populations
2. *A lack of appropriate measures* to assess the relationship between participation and the use of assistive technology

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March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch have concluded an agreement by which data to measure this objective will be included in the NHIS supplement during 2002.

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3. *Insurance coverage/payment policies* that exclude coverage for assistive technology and/or prohibit access to and use of an adequate range of assistive technology
4. *A lack of incentives* (inadequate reimbursement) for industry to invest in research and development for emerging technologies
5. *A lack of financial incentives* in terms of tax breaks for individuals; that is, leasing wheelchairs, depreciation on equipment, low-interest loans amortized over 20-30 years, etc.
6. Appropriate language throughout *Healthy People 2010* must reflect that assistive technology enables people to be independent and to increase their participation in activities they deem to be important.

A. Lack of data
1. *On developing disabilities and disability groups that may not have been seen as benefiting from assistive technology, e.g., people with cognitive disabilities.* "Developing disabilities" refers to "new" or "emerging" disabilities, i.e., people who previously would not have survived particular congenital infectious diseases or injuries, now may expect life spans that approach the typical. This term may also refer to the phenomenon of people

developing disabilities as they age (e.g., reduced vision, hearing, and mobility) or the influence of AT on the development of young children; perhaps AT increases their social and intellectual capacity. We do not have longitudinal data comparing a group of well equipped versus poorly equipped children using social and academic outcome measures.

2. *On who owns, leases, rents or has access to and use of technology for specific activities (education, work, athletic events).* We need to collect data on ownership to provide a base rate for tracking progress in this area. For example, if AT were to be moved from being a medical deduction to the 1040 Tax credit section, we could predict an increase in personal ownership. However, this would require identifying a current rate of ownership prior to making the tax code adjustment.

   As it pertains to this lack of data, the second BRFSS disability question (see Objective 6.1) does not capture the following information.
   - It is not possible to discern which people with disabilities require equipment, but do not *have* the equipment. If one recognizes a need for equipment, an individual could answer "yes," but the question does not indicate whether the people with disabilities have the equipment they need.
   - It is not possible to discern which people with disabilities require equipment, but cannot *use* the equipment they have. Many people with disabilities have devices that do not work for them. The NRHCHDR has conducted studies on this issue. If an individual knows he/she needs the equipment, that person could answer "yes," but, as phrased, the question does not indicate that the equipment is providing benefit; that is, the question should ask whether the equipment is useful or whether the interviewee needs something else.
   - People with disabilities who use equipment that is not "special." Most people with disabilities use at least some equipment to accommodate their disability in a way that was not specifically designed for that purpose or use. Also, some equipment with universal design features—although not specific to disability—accommodates and provides function and benefit for people with disabilities.

3. *On personally devised assistive technology and accommodations, or family innovations.* These types of data would be highly variable and very difficult to track without conducting a large longitudinal study. Even employing that approach, the heterogeneity in AT and type of limitation studied would render the study, at the least, challenging to undertake. However, with the right questions, acknowledging the ingenuity and contributions of people with disabilities, these data could be measured.

4. *On the effects of AT in preventing and treating secondary conditions.* Establishing base rates for "high tech" devices would be relatively easy to do since they have yet to be installed in large numbers or purchased (e.g., new multi-functional wheelchairs, communication devices, etc.)

B. Lack of appropriate measures.
   We need measures for quantitative functional participation assessment. To the best of our knowledge, a survey or assessment tool does not exist that provides the base rate for a single

type of AT for ownership, shelf life, durability, use, or change in the social participation in a wide array of activities. The Functional Measure of Independence (FIM) is limited in the types of activities it covers; the independence score is lower with AT use and no attention is given to the type of AT used. The Food and Drug Administration (FDA) penalizes new devices that provide for increased participation (in areas not covered by the Functional Measure of Independence [FIM]) because the criteria for approving medical devices are based on already-existing equipment. For example, the new transporter, the IBOT, provides the user with vertical as well as enhanced horizontal movement capacity, but no existing measurement tools can cite this innovation. Although the Technology Act of 1988, as amended, has created state agencies, none of them maintains a statewide tracking procedure of any device. No assessment of a need for AT exists that crosses boundaries for limitation and activity.

C. Reimbursement policies are inadequate, **limited to categories that narrowly define medical necessity, and are biased against the participation element of health as posed in *HP 2010*.** Both public and private health insurance systems have outdated policies and processes for assessing new assistive technology. As a result, new technology is routinely denied coverage and reimbursement.

D. Rephrase Objective 6.11 in order to strengthen the focus on participation. As stated in our introduction, the revised objective would read: *Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed to participate in home, school, work or community activities.*

E. Lack of incentives for industry to engage in research and development of assistive technology. This problem is primarily due to the lack of reimbursement for the devices, especially for innovative technologies that do not fit into existing funding schedules and categories.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch have concluded an agreement by which data to measure this objective will be included in the NHIS supplement during 2002.

III. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Major programs
1. To develop a prototype program, we first need a measurement system, grounded in the concept of participation, that looks at:
   a. activities,
   b. choice,
   c. frequency,
   d. satisfaction,
   e. importance

f.   access to and use of assistive technology, and

g.   the type of assistive technology used/needed.

2. Literature reviews/meta analyses are needed on:
   a.   current measures for AT use based on the "participation concept"
   b.   prior surveys on assistive technology
   c.   use-disuse/abandonment of assistive technology

3. Studies to identify and develop emerging assistive technologies are needed.

4. Develop a prototype for collecting evidence that has the potential to determine whether use of current or improved assistive technology effects change in participation. Examples are:
   a.   Collection of durable medical equipment (DME) and augmentative communication data regarding assistive technology and participation, and related expenditures; nationally
   b.   Treadmill (CPG) training
   c.   Functional electrical stimulation (FES): bowel and bladder
   d.   Mobility devices
   e.   Pain management devices
   f.   Biofeedback devices
   g.   Assistive technology's role in increasing participation in persons with chronic disease such as diabetes and arthritis
   h.   Technology's role in providing support for/assistance to caregivers of the elderly

5. Requirements that the NIH cohorts include persons with disability and track their need for and use of technology; identify this need for assistive technology as well as what type of technology is actually used.

B. Proposed policies
1.   Universal encounter form to collect information regarding the need for and actual use of assistive technology (Program #4 cited above)
2.   New policies required for reimbursement: Medicare/Medicaid, HMO/PPO (Problem II.3, cited above)
3.   Tax credits: for individuals and for companies; tax code changes at both the federal and state levels; coverage and payments for innovations in assistive technology development (Problem II.5, cited above)
4.   States should be encouraged to enact conflict-of-interest laws to prevent impropriety in the relationship of health care providers who prescribe and sell durable medical equipment.

IV. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. For partners for Program #4 (cited above) we recommend:
   1. Developing the prototype with the federal health agencies (e.g., use the VA system to implement the prototype study for men, and look for partners to include women.)
   2. For prototype studies, we recommend as partners Rehabilitation International (RI), Disabled People International (DPI), and AAPD.

B. For the program involving technology's role in increasing participation in persons with chronic disease such as diabetes (e.g. under Program #4.g., cited above), we recommend partnering with CDC's Center for Chronic Diseases and NIH's The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

C. Partners for working on Problem II.3, cited above, include the long-term disability insurers (LTD) and workers' compensation administrators.

D. Partners for working on Problem II.4, cited above, include the International Trade organizations, the National Science Foundation, the NASA, NIDRR, and NIH, the Bio-Tech Industry, and the NSF and academic alliances.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

A. For the programs described above, as it involves tracking prototypes and measurements, we have the following questions and suggestions.
 1. Is NHIS-D scheduled to be conducted again? How can we influence it?
 2. Issue the request for proposal (RFP) in early 2002 to initiate literature reviews and study designs.
 3. Complete designs for prototypes, surveys, and measures by 2004.

B. Reimbursement policies
 1. Track new legislation related to assistive technology and its status
 2. HCFA new technology policy

C. Incentives for industry
Examine records of the SBA and Internal Revenue Service (IRS) for industry development of technology

D. As it regards the assistive technology perspective, suggestions of new mechanisms for tracking progress toward the goal of "Maximizing Quality and Years of Healthy Life" follow.
 1. Track new legislation and status.
 2. Track HCFA payments for AT.
 3. Track policy developments towards decreasing disparity as they regard transportation, housing, and employment.

4. Identify and help to modify current mechanisms used for tracking AT.
5. For HMOs/PPOs, workers' compensation, long-term disability insurance, track payment claims, payments made, and amounts awarded

E. Use accessible public information and industry records regarding AT sales to determine if an increase in the rate of sales parallels the rate of demand for new assistive technology.

Objective 6.12: (Developmental) Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities

Introduction
Data from the National Safety Council show that seven out of 10 workers between the ages of 35 and 65 will experience a disability lasting 3 months or longer.[1] One out of seven will be disabled for 5 years or more before retirement. In addition, Census Bureau data project that by the year 2030, 20% of the population will be 65 or older.[2] Such statistics illustrate the need to educate the public about making adaptations for disability, and that this phenomenon is not exclusive to "people with disabilities" as they are considered in a more traditional sense. Accessibility and usability will need to be understood as an integral part of all design; merely tacking on to designs or buildings an "accessibility" component after the fact will not suffice. Universal design will call for a constant and widespread rethinking of the term "disabled" such that the public increasingly recognizes that the needs for and benefits of universal design apply to all of us.

I. How *practical* are the targeted objectives for implementation by the year 2010?
The *HP 2010* process has strategically worded a developmental objective in 6.12. This objective has a high probability of being retained because of the relative simplicity of the assessment being called for. Practical methods currently exist to quantify subjective reports of encountering environmental barriers. In a statewide population-based survey, The Craig Hospital Inventory of Environmental Factors (CHIEF)[3] has been validated for use by people with and without disabilities. Data from that application (as well as data from other surveys) have demonstrated that many people encounter environmental barriers; people with disabilities encounter environmental barriers more frequently, and consider them to be more problematic, than do people without disabilities.

While the wording of the specific objective increases its practicality for measurement, the intent of the objective is more substantial. A more general phrasing of the broader objective might be "*Increase the amount, ease, and quality of participation for people with disabilities through the reduction of environmental barriers in home, school, work and community settings.*" While the more general wording would be more difficult to assess because of its implied objective measurement of physical, attitudinal and policy barriers in multiple settings, the strategy to achieve either the specific or the more generally stated objective is known to be part of "universal design."

The process of universal design uses a positive, comprehensive and inclusive approach that helps change the view people typically have—that is, that this issue only affects a small minority of people who have minimal potential for full participation. By contrast, universal design demonstrates the potential of people with disabilities when environmental barriers are removed, using techniques that improve the lives of all people. It attempts to eliminate all types of environmental barriers by selecting design, approach and policy solutions that have the widest possible acceptance by the broadest variety of people. Universal design inherently includes

direct insights from people with all types of disabilities and it is strengthened by a combination of bottom-up, grassroots strategies as well as top-down, leadership techniques.

The implementation of universal design principles to meet these specific and general objectives is not only practical, it is essential. Universal design is a concrete approach to reducing environmental barriers and it is usually one of the easiest and most economical ways to improve societal participation by people with disabilities. In a broad interpretation of universal design principles, attitudinal and policy barriers, as well as physical barriers, are addressed. Universal design is a positive mechanism for minimizing the segregation of people with disabilities from the general population. By facilitating greater participation of people with disabilities in public settings, public attitudes toward people with disabilities can become more positive due to increased exposure. Since universal design principles are best implemented through a broad systemic and policy-based approach rather than on an individual case level, major macro-level policy change will be more likely to occur.

March 2001 STATUS UPDATE: CDC's National Center for Health Statistics (NCHS) and Disability and Health Branch have concluded an agreement by which data to measure this objective will be included in the NHIS supplement during 2002.

II. What are the major *problems* in addressing this objective?

A. Problems to overcome in meeting the *specific* goals of Objective 6.12 include the following.

1. Conceptual and operational definitions of environmental barriers and universal design are vague, and common usage of the terms is often limited to physical barriers in the built environment.

2. There is no consensus among disability researchers on the most appropriate items or measures to use in assessing perceived environmental barriers in population surveys.

3. Current survey research methods are not yet fully accessible to the broad range of people with disabilities (e.g., people with cognitive impairments cannot answer the questions in the CHIEF[3] chart).

4. Aggregation of individual data cannot fully reflect the underlying heterogeneity of diverse subgroup viewpoints.

B. Problems to overcome in meeting the more *general* goal of Objective 6.12 include the following.

1. It does not seem effective to fully measure environmental barriers merely through health-related population surveys. Even an ideal subjective measure of comprehensive

environmental barriers is not equivalent to using more objective measures of community environments; both are needed. There is no national information system that is designed to focus on environmental barriers; health surveys are individually based, not community based.

2. On a national basis, interventions to improve community environments for people with disabilities are scattered and not well organized.

3. Resources, personnel and methodologies to implement environmental change are limited.

4. In general, reducing environmental barriers is not high on the list of major problems cited by the general population, but it is a top priority on the list cited by people with disabilities. This discrepancy must be bridged to solve the problem.

5. Additional research is needed to investigate the underlying theory of and mechanisms for increasing participation by means of decreasing environmental barriers.

6. From an ergonomic perspective, there is a lack of comprehensive data on the full range of human functioning.

7. There is no single mechanism or central agency which has been legislatively charged with addressing the issue of removing environmental barriers for people with disabilities at the federal or state levels; vague responsibilities are currently shared among education, health and human service agencies.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. Designers, builders, architects, and planners
B. Interior decorators and facility managers
C. Developers of intentional communities
D. Centers for universal design
E. Universal design practitioners
F. State level offices of disability and health
G. Federal agencies such as the departments of housing, transportation, education, labor, health and human services, and justice
H. Area agencies on aging and AARP
I. Environmental health representatives
J. Employers, human resource directors, and school administrators
K. The National Ad Council and media corporations
L. Politicians and community leaders
M. Churches, synagogues and other faith-based communities; and voluntary nonprofit organizations
N. A variety of disability researchers, health survey developers, and people with disabilities
O. Access Board

P. University researchers

Q. State Technology Act Projects and the Association of Technology Act Projects (ATAP)

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. Research and planning
1. Investigate the range of human functioning among the total population with implications for environmental design.

2. Incorporate the subjective assessment of environmental barriers into national surveys (see Objective 6.1).

3. Develop and test more objective measures of environmental barriers through the five recent CDC awards to develop measures of the community environment.

4. Apply public health methodologies to a review of existing environmental barriers data in an effort to target environmental interventions with the greatest potential impact.

5. Develop a standardized national measurement process for objectively assessing community environments and enact legislation to implement common data collection.

6. Investigate specific examples of environmental factors affecting the health, participation, and quality of life of people with disabilities.

7. Institute objective environmental barrier assessments by health departments, beginning with health care facilities, but expanding to schools, work places, and the community in general.

B. Partnerships
Highlight communities that are particularly effective in improving community environments.

C. Funding
Invigorate the government-funded state disability and health programs to address environmental barriers by providing assessment tools and funding pilot interventions to reduce barriers; also, expand the capacity building grants to all fifty states.

D. Public education
1. Raise expectations of what people with disabilities can and should do.

2. Disseminate all public health material in multiple formats (e.g., educational materials, news briefs, memos, resource lists, etc.)

3. With the assistance of the National Ad Council, develop a public relations campaign that targets attitudes toward people with disabilities; incorporate the message that universal design is good for everyone while being especially helpful to people with disabilities because it increases participation and choice.

4. Establish a national clearinghouse on universal design materials and publish comprehensive guidelines for implementing universal design principles in home, school, work and community settings.

E. Professional education

1. Expand the perspective of health, education and social service providers to incorporate the broader environmental context.

2. Establish a clearinghouse on universal design materials and publish comprehensive guidelines for implementing universal design principles in home, school, work and community settings.

3. Some architects suggest that one of the greatest obstacles to accessible (and attractive) design is the paucity of ADA-compliant products for the home. We recommend creating a means by which architectural groups can contribute to a knowledge database for the manufacturing industry to produce and promote such products.

F. Implementation

1. Create a presence on disability in the White House to review all public policy with regard to its impact on people with disabilities, and coordinates national policy on ADA compliance and reducing environmental barriers to participation.

2. Shift to systemic solutions for reducing environmental barriers in much the same way that anti-tobacco campaigns have shifted from assisting individual smokers with smoking cessation to advocating for smoke-free environments.

3. Incorporate systematic consideration of universal design principles in the urban-planning and building-permit process.

4. Implement universal design principles in the curricula of schools of design, architecture, and planning.

5. Advocate ADA and IDEA enforcement by the Department of Justice.

6. Develop a standardized national measurement process for objectively assessing community environments and enact legislation to implement common data collection.

G. Advocacy

As with Implementation, create a presence on disability in the White House to review all public policy with regard to its impact on people with disabilities, and coordinates national policy on ADA compliance and reducing environmental barriers to participation.

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

Progress in achieving Objective 6.12 can be measured by the quick implementation of subjective environmental barriers questions in national surveys (see March 2001 status update box under section 6.12, I. This will establish a baseline and a change tracked over time, followed later by the implementation of more objective community environmental assessments which are currently under development.

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Objective 6.13: Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers

Introduction
There is an emerging recognition of the importance of health promotion for people with disabilities, and the elimination of health disparities is a priority public health issue. Strong emphasis must be placed on engaging and expanding the role of public health agencies in addressing health disparities between people with disabilities and the general population. As a natural component of the charge of state health departments, Objective 6.13 calls for the full integration of preventive health services, health promotion, and chronic-disease prevention programs for persons with disabilities. By providing funding, technical assistance, and strong public health leadership, expansion of disability surveillance and state programs should serve as the foundation for the achievement of *HP 2010* goals for people with disabilities.

Technical note
Edited excerpt from the 6.13 Working Paper: "*The needs of people with disabilities and caregivers should be addressed by public health activities.[*] In a telephone survey, 23 percent of all U.S. households included at least one caregiver. While not all people with disabilities are dependent on the services of a non-paid (usually a family member) or paid caregiver, meeting the needs of those who benefit from personal assistance cannot be easily separated from the needs of people who provide assistance. Whether caring for infants, children, or adults with disabilities or for the increasing number of people who become activity-limited as they grow older, the caregiver is an important health component."*

We acknowledge the merits of assessing the health needs of caregivers, and the value of health promotion programs designed to reach this large and diverse population. However, adequate data regarding best practices to address these needs are currently unavailable. Hence, we propose focusing on caregiver issues for a developmental objective and will respond to the strategic planning questions below in light of the identified health-related needs and infrastructure for people with disabilities across the life span.

I. How *practical* are the targeted goals for implementation by the year 2010?
The goal to establish public health surveillance and health promotion programs for people with disabilities in all fifty states and the District is reasonable and measurable. (See Concern #1)

Assumptions
We are defining "public health surveillance and state health promotion programs for people with disabilities" based on characteristics reflective of some/all of the existing 14 CDC-supported

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[*] Figures from the 1997 Survey on Income and Program Participation (SIPP) conducted by the US Bureau of the Census indicated that 19.7% of the population reported having some level of disability or activity limitation. In addition, 3.8% reported needing personal assistance with one or more ADLs or IADLs.

state-capacity grantees. The expertise of those involved in existing programs should be used in expanding, deepening, and disseminating effective models.

Concern #1:
It will be necessary to moderate the potentially competing interests of "vertical versus horizontal" growth. There was some support for seeing a smaller number of truly comprehensive, quality programs established to develop and test "best practices." This approach contrasts with that of developing 51 potentially more superficial and less effective state programs. At the same time, the objective currently calls for horizontal growth and such an approach is in line with a systematic, national response to the identified health disparities for persons with disabilities.

Recommendation to manage Concern #1:
Establish an interim benchmark of 25 states to have achieved this objective by 2005. This would serve as a springboard for further expansion and development of 51 effective models by the target year 2010.

Concern #2:
It is acknowledged that the health and well-being of family caregivers is a critical issue. However, we do not view as practical the achievement of the targeted objective of 51 public health surveillance and health promotion programs for caregivers by the year 2010. Currently, there is no established mechanism for public-health surveillance of the health-related needs of caregivers; nor is there a defined locus for responding to identified needs, thus making this component of Objective 6.13 developmental in nature. We do not currently know which issues are of most pressing concern to caregivers. From a public health standpoint, the health and well-being of family caregivers is of critical importance. There is extensive research on the physical/mental/emotional impact of family caregiving and we feel that at this developmental stage, helping to identify the priority health-related needs of caregivers is where the focus should be placed. This may lead to support for enhanced coverage and improved employment supports for paid providers of care, for home modification, or for assistive technology, rather than other health-promotion activities specifically aimed at addressing the health and quality of life of caregivers.

The responsibility of the government agency relative to the needs of family caregivers is not well defined; nor does the existing agenda for family caregivers relate only to Objective 6.13. For example, depression is a major issue for caregivers, and the topic of mental health is directly referred to or implied in many other objectives of *Healthy People 2010* Chapter 6. Should these objectives apply both to the caregiver as well as the person with a disability?

Recommendation to manage Concern #2:
We need to fully acknowledge the role of caregivers and develop an approach for identifying their health-related issues and responding to their health-promotion needs. Support and potential integration of the interrelated issues of family caregiving should be recognized within the national agenda and the following programs within states: state disability and health; chronic disease; traumatic injury; birth defects and developmental disability; aging; and Children With Special Health Care Needs (CSHCN).

Family caregivers are included in Objective 6.13 because of the direct link between caregivers and disabled/chronically ill individuals. Caregivers have their own needs related to their caregiving.

Since there is no national precedent for a public health approach to the basic issues of family caregiving, some realistic goals might be:

1. Moving states and territories to acknowledge that the health/well-being of family caregivers is an important public health issue. Also, this phenomenon impacts our entire health care delivery system because "family" caregivers are the predominant providers of care.

2. Develop a common assessment mechanism and gather other data across states using uniform methods.

Achievement of these goals would be a major accomplishment in the overall efforts toward the well-being of both people with disabilities and family caregivers.

II. What are the major *problems* in addressing this objective?

A. Resources
1. The financial resources currently available are insufficient. States are unlikely to implement programs without dedicated funding for necessary infrastructure, staff, and the data to support those programs. We need to establish a consensus regarding what constitutes "best practices" in state-level programs.

2. There is a lack of influential champions for these issues within both the public health and disability fields.

3. The resources available to supplement or substitute for family caregivers, such as paid personal care attendants (PCA) and respite care, are lacking.

B. Data
1. Only 11 of the 14 currently funded state capacity-granted states collect data through BRFSS in a way that can be reported nationally. The data that are available on the health-related needs and issues for people with disabilities should be more effectively disseminated. (In addition, Puerto Rico, the Virgin Islands, and the Pacific Trust Territories must be included in all aspects of surveillance as well as programs and policies.)

2. We need to define people with disabilities consistently in surveillance/data instruments (See Objective 6.1).

3. Most/all of our sampling/methods exclude the population of people with disabilities in institutional settings. Methods often represent people with specific types of disabilities (e.g., hearing or cognitive impairments).

4. We need to define caregivers consistently in surveillance/data instruments and develop an operational definition of "caregiving" for the *HP 2010* objectives.

5. There are people with activity limitations and caregivers who do not necessarily self-identify.

C. Perspective
1. The traditional bureaucracy-related issues as they pertain to this objective are problematic. State programs are known for high staff turnovers and continual changes in political priorities. Placement within the bureaucracy can be a benefit or a barrier to institutionalizing activities.

2. We need to develop a technical-assistance component in addition to the government to assist states in "readiness." A structure of responsibility for this element would need to be determined.

3. Public health tends to focus on categorical programs rather than social environments. What is called for is a social-ecological approach that is inclusive of the person with a disability, caregivers, social supports (such as spiritual supports, employers), etc. The approach used by WHO for the revision of its disability classification is such a perspective.

4. Within CDC and state health departments, there is limited recognition of the commonality of issues and potential for integrated surveillance and intervention approaches among disability and health programs and those focused on chronic disease, birth defects, developmental disabilities (DD), and injury (traumatic brain or spinal cord injury).

5. The CDC program/categorical hierarchy (i.e., diabetes, traumatic brain injury [TBI], spinal cord injury [SCI], cancer, cardiovascular disease [CVD], DD, birth defects) has not adequately recognized the issues of caregivers, and the program announcements do not currently address the needs of caregivers. A cross-cutting approach is required.

6. The health and well-being of family caregivers is a public health issue. An unpaid health force is providing the majority of care. The issues of family caregivers are inherently different than paid givers of care, as are the specific programs and supports that need to be put in place to promote caregivers' own health. Caregivers need to receive information about how to become more capable caregivers as well as information about the impact of caregiving on the health of the caregiver.

7. The whole emphasis on health promotion for people with disabilities is an emerging area of public health.

8. At times there is tension between advocacy groups focusing on disabilities and those focusing on caregiving. Points of common concern, as well as differences, should be communicated. Where possible, join activities should be instituted.

D. Partnerships, coalitions, and networks
   1. We need to identify, nurture and expand coalitions to advocate for addressing this objective at the national and state levels. There needs to be greater lobbying for increasing resources for disability and health for both people with disabilities and caregiving families.

   2. There is a tendency toward developing condition-specific responses, which can result in further fragmentation and competition among disability and chronic disease-oriented efforts. We hope that in the future there will be more support for cross-disability approaches.

   3. Currently there are no established caregiver agency/consistent networks at the state level. This is a barrier to enabling caregiver emphasis as an integral, focused component of state disability and health programs.

III. Who are the governmental, nongovernmental, private and other Consortium members who could/should be *partners* in implementing this objective?

A. Easily identifiable partners are the public health community including national, state and community programs in chronic disease, such as those for cancer screening, women's health, cshcn, domestic violence, etc.

B. In order to identify the best partners for meeting this objective, undertake an inventory of programs and resources (e.g., fitness providers, mental health programs) that already exist within the community. Identify gaps as an outcome of the inventory.

C. In some states, there are active networks/advocates around caregiver issues. We advise exploring the development of an integrated agenda that addresses the interrelated needs and issues of people with disabilities and caregivers.

D. Universities are sources of disability- and epidemiological-data support.

E. Centers for Independent Living, and disability advocacy and service organizations are essential partners.

F. Private corporations and companies who profit from services and products to people with disabilities and caregivers should be enlisted in underwriting health-promotion efforts.

G. As it pertains to family caregivers, and to moving the focus for states and territories to acknowledge the need to protect caregiver health, logical partners would be currently functioning programs and schools of public health.

H. The American Public Health Association (APHA) should be encouraged to acknowledge that people with disabilities are a population that fares poorly in terms of health disparities.

IV. What are initial *programs*, current or envisioned, and/or *policies* that could help meet this objective?

A. CDC organization
There needs to be a clear commitment on the part of CDC to seek full funding for implementation of this objective. The existing paradigm, which is noncategorical and lifespan-focused, must be maintained in order to build on the emerging state disability and health infrastructure.

B. Data
1. Implement Objective 6.1: *Include in the core of all relevant* Healthy People 2010 *surveillance instruments a standardized set of questions that identify "people with disabilities" across the life span*.

2. In implementing the above from Objective 6.1 as it concerns identifying people with disabilities, consider that a parallel (a standardized set of questions) might also be explored to identify family caregivers.

3. Develop a mechanism for systematically developing data reports comparing people with disabilities to those without, and differences among people with disabilities. There needs to be greater consistency across the states. Data must be released externally to the advocacy community as well as used within the public health community. We suggest translating the data for diverse audiences and disseminating the data to the general public and media. Potential resources are NIDDR-funded projects, the Accessible Society Action Project, and National Center for the Dissemination of Disability Research (NCDDR).

4. Develop publications/public health guidance that describes the implications and applications of the data to health-promotion interventions.

C. Technical assistance
1. To develop improved readiness, provide technical assistance to nonfunded states or states at "planning stages" for programs and surveillance.

2. Fund a network for providing technical assistance/mentors for new states.

3. Give greater emphasis to sharing models and highlighting best practices. Disseminate the lessons learned from the successful states and use those programs as models that should, and can, be replicated.

4. Develop mechanisms for increasing inter-state collaboration, especially around common programmatic issues.

D. Strategic planning
1. Better frame how work will benefit different constituency groups and undertake more aggressive social marketing to different potential partners.

2. Employ more people with disabilities for public health positions within national, state and community settings.

3. Integrate the subject of disability into efforts to address health disparities and the health of minority populations. Include and engage disability experts as consultants in shaping targeted efforts as well as efforts aimed at the general population.

E. Targeted-emphasis funding
In recognition of existing health disparities between people with and without disabilities in relation to many *HP 2010* objectives for the nation, we highly recommend that governmental and nongovernmental funding agencies specifically include people with disabilities as a target population in RFPs. Furthermore, the specific issues of this minority population should be reflected in the policies of relevant public health programs.

F. Promoting awareness
1. Develop mechanisms for promoting to state and federal policymakers an awareness of the public health issues related to people with disabilities. This should include state health directors, legislators, legislative staff, and lobbyists.

2. Assist states in identifying partners (e.g., advocacy groups, community groups) who can advocate the establishment and enhancement of state programs.

G. *HP 2010* objectives
1. Continue to publicize the *HP 2010* objectives for people with disabilities, the use of disability as a demographic variable in related chapters, and the existence of Objective 6.13.

2. Encourage the integration of a disability focus within broad-based state health planning efforts, especially those focused on eliminating disparities.

H. Training
1. Infuse public health training programs with disability content/curriculum in order to train the next generation of public health professionals (epidemiologists, health educators, program managers) with the knowledge base to become leaders in state-based programs.

2. Infuse health professional training programs with content/curriculum on the importance of health promotion for people with disabilities.

I. Disability community
1. Work with Centers for Independent Living (CILs) to integrate health promotion into their agenda.

2. Develop more effective outreach and health education to people with disabilities.

3. Integrate a health focus that includes initiatives to increase access to work and health insurance for people with disabilities.

J. Information and education
Improve health-education and health-promotion materials for people with disabilities both in regard to content and approach. We suggest developing new materials, encouraging general population-oriented materials to better reflect a disability focus, and establishing more effective dissemination channels for both people with disabilities and providers.

K. Cost-effectiveness
1. Demonstrate the benefits of secondary-conditions prevention and the benefits/potential cost-savings associated with health promotion for insurers and employers.

2. Ensure that those who might most benefit from health promotion/disease prevention efforts are not inadvertently excluded due to access and usability barriers. (This could be achieved through implementation of Objective 6.10.)

V. Are adequate mechanisms in place for tracking *progress* towards meeting the targeted goals? If not, what needs to be done to institute such tracking mechanisms?

A. Establish an interim measure
We recommend setting this measure at 25 states to have met this objective by 2005.

B. Surveillance and health promotion for caregivers
Develop a process to explore the options of tracking mechanisms to establish objectives, goals and benchmarks for caregivers.

C. Integration of tribes
Explore options for engaging Native American/tribal populations in work associated with meeting this objective. Establish tracking mechanisms for expansion/inclusion of disability and health programs within tribes. Consider collaboration with the Office of Indian Health Services.

D. Evaluation of quality/effectiveness
We should go beyond a "process count" of the simple "existence" of state disability surveillance and state health promotion programs to address the following questions: How do we define and measure the quality and comprehensiveness of such programs? How can we better measure the

impact of state-capacity programs, including ways to address health disparities, knowledge, and the involvement of the disability community? How can we better measure the impact of state-capacity programs on knowledge and depth of involvement of the public-health community? This will require the establishment of both objective and subjective measurements of public impact.

VI. Conclusion

Full implementation of this objective will result in the refinement and broad dissemination of state-tested tools and approaches for decreasing disparities in health status, and health and wellness provision to people with disabilities. As outlined, implementation of Objective 6.13 will facilitate significant progress for our nation over the next decade toward meeting *HP 2010* objectives both within Chapter 6 and related chapters.

FUTURE

WHERE DO WE GO FROM HERE?
Raymond Seltser, M.D., M.P.H.
Emeritus Dean, Emeritus Professor of Epidemiology
University of Pittsburgh Graduate School of Public Health

The material contained in the 13 workgroups' reports is the core of this document. An overview of the issues covered by the workgroup reports has been presented in the synthesis in the preceding chapter. While this synthesis provides a snapshot of the material covered in the reports themselves, it is important to remember that the specific ideas in these 13 reports represent the combined input of an unusually dedicated and competent group of disability experts, and many of the ideas presented have enormous potential for shaping the direction of the strategic planning process needed to implement the goals of Healthy People 2010.

The December 2000 symposium was intended as the first step in this strategic planning process, and is to be followed by a larger conference that will convene representatives of the key "stakeholders" in the effort to reach the targets set for the 13 disability-related objectives. The purpose of that conference will be to a) establish priorities for action; b) elaborate programs and policies which need to be undertaken; c) specify the actions that need to be taken to launch such programs and put appropriate policies in place; and d) recommend the appropriate administrative and logistical support needed to implement the strategic plan.

The conference participants will be divided into six (6) primary groups, each of which will be responsible for developing the strategic plan for the objectives included in their "thematic group." The objectives have been grouped according to the following six themes:

Data: Objectives 6.1 (Standard definition of people with disabilities in data sets) and 6.13 (Surveillance and health promotion programs)

Children: Objectives 6.2 (Feelings and depression among children with disabilities) and 6.9 (Children and youth with disabilities included in regular education programs)

Social/emotional health: Objectives 6.3 (Feelings and depression interfering with activities among adults with disabilities), 6.4 (Social participation among adults with disabilities), 6.5 (Sufficient emotional support among adults with disabilities), and 6.6 (Satisfaction with life among adults with disabilities)

Participation/work: Objectives 6.8 (Employment parity) and 6.12 (Environmental barriers affecting participation)

Environment/accessibility: Objectives 6. 10, (Accessibility of health and wellness programs), 6.11 (Assistive devices and technology), and 6.12 (Environmental barriers affecting participation)

Caregivers/long-term care: Objective 6.7 (Congregate care of children and adults with disabilities)

Within each thematic group there will be subgroups that are responsible for developing specific actions to implement the workgroups' recommendations. These action strategies will be grouped according to the following categories:

1. Data Collection
2. Coalition Building
3. Legislative Initiatives
4. Promotion and Initiation of Research
5. Public and Professional Education and Enlightenment

It is anticipated that the major portion of the time will be spent on obtaining consensus from the groups on the specific actions and recommendations that have been presented to each of the groups as Draft Policy Papers. These papers will have been prepared and distributed well in advance of the conference.

The specific proposals presented by each of the 13 workgroups represent the basis for the development of those Policy Papers; they are contained within the answers to Question IV, which was posed at the December 2000 symposium: *What are initial* programs*, current or envisioned, and/or* policies *that could help meet this objective?*

DATA

***Objectives 6.1 (Standard definition of people with disabilities in data sets) and 6.13
(Surveillance and health promotion programs)***

For each of the following, specify the actions that need to be taken to launch such programs and
put appropriate policies in place; establish priorities for action; and recommend the appropriate
administrative and logistical support that will be needed to implement the strategic plan.

DATA COLLECTION
1. Immediately identify opportunities to begin tracking people with disability in major surveys.
Identify opportunities by creating an inventory of surveys and processes for target data collection
(the timeframe for this activity is immediate and ongoing). This relates to identifying health
objectives not only in Chapter 6, but also in other *HP2010* chapters that relate to people with
disabilities. Related tasks include enumerating the instruments by disability-related objective,
contacting the parties responsible for achieving the health objective, and taking whatever steps
are needed to add the disability-identification questions to these instruments. The timeframe for
this is short because of the need to identify at least one data point prior to mid-course review.

2. Review and prioritize the other *HP2010* objectives to identify those with the highest yield and
highest priority for data collection. Partners for this activity would be those listed in *HP2010* as
lead agencies on other objectives that specifically identify people with disabilities.

3. Develop a mechanism for systematically developing data reports based on disability. There
needs to be greater consistency across the states. Data must be released externally to the
advocacy community, as well as used within the public health community. We suggest
translating the data for diverse audiences and disseminating the data to the general public and
media.

COALITION BUILDING
1. Support Objective 6.1 with specific staff who have dedicated time for activities related to this
agenda. These activities will require public and private partners to conduct and monitor the
progress of Objective 6.1. For this reason, the workgroup requests the ongoing supervision of
progress with Objective 6.1. The lead agency on this list of partners would be CDC. Additional
partners might be NIDRR (Disability Statistics Rehabilitation Research and Training Center at
UCSF) and academic research groups.

2. Develop a strategy to foster cooperation with other programs that previously have not linked
or cooperated with the disability community and their objectives. The traditional public health
infrastructure has viewed the population with disability as either beyond its scope or the
responsibility of other agencies. Efforts are needed to persuade public health agencies that
people with disabilities are a subset of the population and the health of people with disabilities is
a public health concern. This activity will require identifying incentives, awards, public relations
programs and strategies, and advocates.

3. Foster collaboration with and among objective-specific programs (e.g., diabetes programs).

4. Develop mechanisms for increasing inter-state collaboration, especially around common programmatic issues.

5. Assist states in identifying partners (e.g., advocacy groups, community groups) who can advocate for the establishment and enhancement of state programs.

6. Work with CILs on integrating health promotion into their agenda.

7. Explore options for engaging Native American/tribal populations in work associated with meeting this objective. Establish tracking mechanisms for expansion/inclusion of disability and health programs within tribes. Consider collaboration with the Office of Indian Health Services.

8. Develop mechanisms for promoting an awareness of the public health issues related to people with disabilities among policymakers at the state and federal levels. This should include state health directors, legislators, legislative staff, and lobbyists.

LEGISLATIVE INITIATIVES
1. Promote and educate Congress on disability-related issues and their overall relevance in health and human rights policies, including the need for data. Partners for this activity include nonprofit private agencies and disability advocacy groups.

2. There needs to be a clear commitment on the part of CDC to seek full funding for implementation of this objective. The existing paradigm, which is noncategorical and lifespan-focused, must be maintained in order to build on the emerging state infrastructure.

3. Insert language in government grant proposals and policies that promote the targeting of people with disabilities and reduction of health disparities as a subset of activity.

4. Assist states in identifying partners (e.g., advocacy groups, community groups) who can advocate for the establishment and enhancement of state programs.

5. Encourage the integration of a disability focus within broad-based state health-planning efforts, especially those focused on eliminating disparities.

6. Integrate a health focus with initiatives to increase access to work and health insurance for people with disabilities.

PROMOTE AND INITIATE RESEARCH
1. Develop a research agenda for constructing a toolkit of optimal disability measures. Develop new measures and address measurement issues such as validation. While the consistent questions proposed above begin the process, this activity is intended to produce measures that

are more completely based on the WHO's *International Classification of Functioning, Disability, and Health (ICF)*.

2. Crosswalk current tracking research. Develop recodes for variables that will assist in interpretation among surveys. An interpretation of the primary measures and other disability definitions must be undertaken.

3. Promote research on the methods of estimating the prevalence of disability in undercounted groups (e.g., institutions, children, and among those with sensory impairment).

4. Demonstrate the benefits of secondary-conditions prevention and the benefits/potential cost-savings associated with health promotion for insurers and employers.

5. Surveillance and health promotion for caregivers: Develop a process to explore the options of tracking mechanisms to establish objectives, goals and benchmarks for caregivers.

6. Evaluation of quality/effectiveness: Go beyond a "process count" of the simple "existence" of state disability-surveillance and state health-promotion programs. How do we define and measure the quality and comprehensiveness of the program? How can we better measure the impact of state-capacity programs, including ways to address health disparities, knowledge and the involvement of the disability community? How can we better measure the impact of state-capacity programs on knowledge and depth of involvement of the public health community? Include measurements for assessing the subjective perception of public impact.

PUBLIC & PROFESSIONAL EDUCATION AND ENLIGHTENMENT
1. Promote the value of viewing and defining disability as a demographic variable. Promote the understanding of disability as a demographic descriptor with heterogeneity, similar to other grouped classifications such as ethnicity/race or sex.

2. Promote with other programs and public health entities (e.g., state health departments) the concept of identifying people with disability as a select population for *HP2010* objectives, related to the goal of reducing health disparity. This activity will require support through an identified or developed educational process. Partners for this activity include NIDRR and the general public health community—not only as a partner but also as a focus for the activity's attention. Targets for this activity include ASTHO and CSTE.

3. Review and triage the published "leading health indicators" package for *HP 2010* and identify areas where the disability community is overlooked. Disability needs to be promoted as a demographic component for data reports and indicators, especially as it applies to disparities. Target as partners the lead agencies of these indicators.

4. Promote media and scientific dissemination of disability statistics to publications that include MMWR and other scientific and lay targets, particularly those having a broad public-health audience. Partners for this activity include the Center for An Accessible Society

5. Fund a network for providing technical assistance/mentors for new states.

6. Better frame how our work will benefit different constituency groups and undertake more aggressive social marketing to different potential partners.

7. Identify and recruit people with disabilities for employment in public health positions within national, state and community settings. The subject of disability needs to be integrated into efforts to address health disparities and the health of minority populations. These experts need to be included and engaged as consultants in shaping targeted efforts as well as those aimed at the general population.

8. Infuse public health training programs with disability content/curricula in order to train the next generation of public health professionals (epidemiologists, health educators, program managers) with the knowledge base to become leaders in state-based programs. Infuse health professional training programs with content/curricula on the importance of health promotion for people with disabilities.

9. Improve health education/health promotion materials for people with disabilities both in regard to content and approach. Establish dissemination channels for both people with disabilities and providers.

CHILDREN

Objectives 6.2 (Feelings and depression among children with disabilities) and 6.9 (Children and youth with disabilities included in regular education programs)

For each of the following, specify the actions that need to be taken to launch such programs and put appropriate policies in place; establish priorities for action; and recommend the appropriate administrative and logistical support which will be needed to implement the strategic plan.

DATA COLLECTION

1. Increase providers' access to technology to enhance data collection (e.g., use of the Internet, Palm Pilots, other mechanisms to record data, or access information). Electronic data entry should be piloted.

2. Look at data from states that have already achieved this objective so that these programs may serve as models for other states.

3. Look at dissemination mechanisms and develop them in more consumer-friendly formats.

COALITION BUILDING

1. Implement mental health promotion programs for children with special health care needs through community-based settings including schools, faith-based communities, community clubs).

2. Train multiple professional groups on mental health issues and needs. (includes ability to identify kids with conditions or risks).

3. The Office of Special Education and Rehabilitative Services (OSERS) has several partnership projects involving the family, teachers, policy makers, school administrators, free appropriate public education (FAPE), and The IDEA Local Implementation by Local Administrators (ILIAD) Partnership that could be used as examples.

LEGISLATIVE INITIATIVES

1. Adopt the UN Convention on the Rights of the Child, which defines response to the health needs of children as a basic societal responsibility.

2. Adopt a national policy recognizing the universal need of families of children with special health care needs for individualized supports. Note that this concept builds upon, but goes beyond, the AAP's "medical home" concept.

3. Establish parity in the financing of mental and other health services. Adopt funding policies to ensure that the way funding is distributed to states and local education agencies (LEAs) does not provide inadvertent disincentives for including children in regular classrooms.

4. Review Medicaid funding and policy; the cost of doing paperwork outweighs the funds yielded.

5. Review practice acts for various professions to see if they impact provision of services (e.g. delegation to other providers).

6. Consider the impact of zero-tolerance educational policies (pertaining to violence) on the ability to bring medically related equipment to school (e.g., for diabetic care).

7. Review the placement policies that are built upon IDEA and the importance of choice—that is, family/student choice.

8. Emphasize reformulation of special education as a service, not a program.

PROMOTE AND INITIATE RESEARCH
1. Replicate the Early Intervention model (which combines family services, family-to-family support and therapeutic services for the child in as integrated a setting as feasible) for other age groups. Model may be particularly important for children and families at key transition points: preteen to teen, school to work.

2. Formulate best-practice research and piloting, and synthesize what is the best practice to achieve these goals.

3. Continue research in how technology can support delivery of care.

4. The CDC should do an analysis of the total cost of maximizing educational needs of students with disabilities, and should conduct a study to evaluate the total cost of not maximizing optimal functioning of people with disabilities.

PUBLIC AND PROFESSIONAL EDUCATION
1. Training of frontline providers is needed on the identification of children with mental health issues and needs.

2. Government and societal sectors (including, but not limited to public health) need to recognize that child mental health is a shared responsibility, and not "someone else's" job.

3. Review school curricula; for example, curricula currently focus almost exclusively on academic skills, but do not incorporate functional academic and other life skills needed for productivity and independent living.

4. *Universal design:* technology might benefit other students, not just those with disabilities (e.g., texts in alternative formats or those that are readily adapted to different levels and needs; teacher guides; variable presentation modes). Develop a mindset that focuses on what would help

everybody and is not merely tailored to students with disabilities. *Physical access:* focus on universal design in modernization activities as well as new building.

5. *Public awareness campaigns*: prepare families who do not have disabilities for the increasing presence of children with disabilities in regular education programs.

SOCIAL/EMOTIONAL HEALTH

Objectives 6.3 (Feelings and depression interfering with activities among adults with disabilities), 6.4 (Social participation among adults with disabilities), 6.5 (Sufficient emotional support among adults with disabilities), and 6.6 (Satisfaction with life among adults with disabilities)

For each of the following, specify the actions that need to be taken to launch such programs and put appropriate policies in place; establish priorities for action; and recommend the appropriate administrative and logistical support that will be needed to implement the strategic plan.

DATA COLLECTION
1. Develop instruments and methods that can measure depression and stress across the population, including individuals with disabilities.

2. Given the data-driven nature of this entire effort, the workgroup strongly recommends that all survey and/or reporting instrumentation be expanded to improve their levels of sensitivity to racial, ethnic and cultural dimensions of the US population. The workgroup asserted that national data sets serve mostly as "beacons" of social conditions rather than attempting to be true research instruments.

3. The QOL data-collection instruments must be culturally sensitive. Special efforts must be made to ensure that the random sample is truly reflective of the disability community.

4. Create data beacons within national instruments to identify decreasing interactions among target populations within community settings.

5. Current national data set measurement instruments are too limited when focused on mental health.

6. Measurement difficulties will arise because "social integration and social isolation" mean different things to different people due either to a too-strict definition or cultural norms.

7. Conduct a national conference to develop consensus on a definition of Life Satisfaction along with recommendations for measurement.

6. Provide safeguards to ensure that measurement instruments reflect responses from the individual with the disability and not a proxy.

7. All 50 states need to use BRFSS.

COALITION BUILDING

1. Develop a coalition of agencies to assess and address problems/solutions, and to develop a blueprint to accomplish parity.

2. The workgroup suggests that involved partners devise methods of increasing emotional support within the family unit, and among family caregivers and other caregivers, for the purposes of peer supports and religious/spiritual support. Activity management will vary at federal, state or local levels (i.e., governmental, nongovernmental, private, and commercial levels). Certain federal and state groups and organizations, which act as "enabling powers," will need to allow local activities to be designed to address these social integration issues. Developing social integration programs may take considerable time, and thus may not easily stay up-to-date with the evolving needs of people with disabilities.

3. Move all agencies and organization from liaisons of cooperation to liaisons of collaboration regarding disparities in general and social integration in particular.

4. City and regional planning groups should be brought into the role of ensuring that building projects meet accessibility guidelines.

5. All recreation programs (city, county, YMCA, etc.) should be accessible and usable, and there should be a means of assessing the status and methods of implementing changes, and a method of monitoring the degree of change over time.

6. The DOT should revisit their national assessments of access to transportation by households without cars in order to assess access to transportation by people with disabilities and the uses of transportation; include a minimum assessment of the effects of access, or its lack, on QOL issues.

7. Create incentives for places of worship and other community-life organizations to reach out and support participation of persons with disabilities.

LEGISLATIVE AND POLICY INITIATIVES

1. Encourage reimbursement policies that would "make prevention pay," such as Medicaid policies that provide adequate compensation for professional providers but that also incorporates reimbursement of "peer counselors" who deliver demonstrated programs (e.g., Seligman's *Learned Optimism* and other programs, such as *Living Well with a Disability*).

2. Equalize Medicaid policies to offer mental health services that address this objective's problem by providing reimbursement for individual and group services.

3. City and regional planning groups should be brought into the role of ensuring that building projects meet accessibility guidelines.

4. Put more resources into enforcement of current legislation to promote full access and social participation of persons with disability (i.e., disability civil-rights laws).

5. Provide meaningful tax credits and incentives for businesses on research, development and service programs to help achieve social participation of persons with disabilities.

6. Increase caps in Medicare/Medicaid and private insurance policies for assistive services and equipment.

7. Reduce the cap on medical expenditures for tax deductions for people with disabilities.

8. Provide tax deductions/credits and loan policies for persons with disabilities for procurement of goods and services that promote social participation (e.g., vans, assistance services, assistive technology, etc.).

9. Include universities and colleges in eligibility for community development grants for integrated social participation of persons with disabilities.

10. Create incentives for places of worship and other community-life organizations to support participation of persons with disabilities.

11. Develop new or amended policies related to access that recognize the importance of a three-part definition that includes physical, time and opportunity aspects, which promote inclusion.

12. Pass into legislation the proposed MICASSA bill.

13. Federal and state governments must identify and remove existing disincentives to family and community living (e.g., losing health care when you work a "real" job).

14. The federal government should commit to a policy of people being able to "age in place" so that services come to people rather than making people move to where the services are provided. This policy and principle is well established in aging research literature, and should also benefit people with disabilities as they age**.**

15. Federal and state governments must develop commitments and policies to ensure an adequate workforce.

16. Dramatically increase the amount of affordable, accessible housing, and assistance with housing modifications and equipment.

17. Any individual with a disability, or family with a disabled member, who is eligible for family or community support should receive those supports within a reasonable period (90 days).

PROMOTE AND INITIATE RESEARCH
1. Develop instruments and methods that can measure depression and stress (related to cognitive and communicative impairments, e.g., learning domain) within the population of individuals with disabilities.

2. All recreation programs (city, county, YMCA, etc.) should be accessible, and there should be a means of assessing the status and methods of implementing changes, and a method of monitoring the degree of change over time.

3. Investigate, document and disseminate best practices in the for-profit corporate sector for universal design.

4. Promote technology transfer research and development.

5. Devise survey/reporting measurements responsive to the breadth and diversity of social/emotional support definition; one that is sensitive to cultural and ethnic diversity for the monitoring of persons with or without disability experiencing decreasing social integration.

6. Create and assess a method of increasing emotional support within the family unit, family caregivers, other caregivers, peer support, and religious/spiritual support.

7. Conduct a national conference to develop consensus on a definition of life satisfaction along with recommendations for measurement.

8. Advocate for research on federally funded universal design zones. Everything in that zone would be environmentally stellar for persons with disabilities. This could serve as a control trial to test how a barrier-free and accessible environment affects the life satisfaction of persons with disabilities. The control group would be different but measured in a similar city that does not possess the treatment variables. Measuring differences in life satisfaction reports could serve to enlighten those who could make a difference.

PUBLIC AND PROFESSIONAL EDUCATION
1. Use peer interventionists to teach self-management therapy for behavioral management of depression. Training for large groups could be done through CILs.

2. Web-based self-management needs to be developed but there should be "certified" sites that present useful information for consumers, family, and providers. Model these efforts on procedures that are used by APA, JCAHO, etc. Increase consumer awareness and training such that there is greater understanding and potential for evaluating information on the Web that purports to treat mental health.

3. Providers and others need awareness of symptoms and reinforcement for referrals.

4. Provide training in disability issues to cross-cutting professional service providers so that they come to understand the risks and response strategies.

5. Encourage/require the health care professions to include assessment of social participation/support (as well as mental and physical health) as part of routine care; this holds implications for training in the medical and health care fields and links to overall health.

6. Training programs for health care and educational professionals should implement courses to enable their students to reassess their biases toward individuals with disabilities.

7. Employer-based wellness programs need to include components that address disability and the needs of people with disabilities. This is consistent with employer movements to maintain employees as a cost-management and productivity strategy.

8. The media need to be rewarded for their progress and continue to be exhorted to provide positive portrayal of disability to the broad public and, by inclusion, by people with disabilities.

9. Investigate, document and disseminate best practices in the for-profit corporate sector for universal design.

10. Promote broader provision of interpreter services to include social activities of publicly funded conferences and meetings as well as recreational activities.

11. Encourage understanding of the needs for "emotional support" as a community issue.

12. Build disability awareness across "institutional settings/practitioners"(e.g., medical, educational, employment and commercial settings).

13. Market the message of social integration to minority and culturally diverse populations.

14. Bring public relations agencies to a conference and reframe their image of people with disabilities. Conduct a sensitivity training, for example, looking at the lives of individuals with disabilities.

15. Encourage CARF, JCAHO, and the other accreditation organizations to include specific standards regarding the tracking of life satisfaction in existing program evaluation and quality assurance tools.

16.. Target journalism students for education on disability issues. Encourage people with disabilities to enter journalism professions.

ENVIRONMENT/ACCESS

Objectives 6. 10 (Accessibility of health and wellness programs), 6.11 (Assistive devices and technology), and 6.12 (Environmental barriers affecting participation)

For each of the following, specify the actions that need to be taken to launch such programs and put appropriate policies in place; establish priorities for action; and recommend the appropriate administrative and logistical support that will be needed to implement the strategic plan.

DATA COLLECTION

1. Integrate with current data collection activities and foster inclusion of the disability-identifier questions (*ICF* projects, BRFSS, National Immunization Survey [NIS], Youth Risk Behavior Survey [YRBS], NCHS).

2. Encourage HCFA to include functional assessment on patient encounter forms. The measurement system should be grounded in the concept of participation, looking at activities, choice, frequency, satisfaction, access to technology, and type of technology used/needed. Create a universal encounter form to collect information regarding the need for and actual use of technology.

3. Include assessment of environmental barriers in BRFSS.

4. Develop a standardized national measurement process for objectively assessing community environments, and enact legislation to implement common data collection.

COALITION BUILDING

Search for other options for health and wellness funding. What is available in the private sector?

LEGISLATIVE INITIATIVES

1. Expand Medicaid funding for health and wellness.

2. Create incentives for programs and facilities for ADA compliance (e.g. tax deductions for inclusion; and health and wellness programming and accessibility; wrap-around federal credits; fitness activity credits).

3. Include criteria for accreditation standards for professions (all aspects of health, wellness, etc.).

4. Tax credits: make them available for individuals and for companies; tax code changes, federal and state; coverage and payments for innovations in technology development.

5. Advocate for ADA and IDEA enforcement by the Department of Justice.

6. Institute objective environmental barrier assessments by health departments, beginning with health care facilities, but expanding to schools, work places, and the community in general.

7. Create a presence on disability in the White House to review all public policy with regard to its impact on people with disabilities, and coordinates national policy on ADA compliance and reducing environmental barriers to participation.

8. Develop a standardized national measurement process for objectively assessing community environments, and enact legislation to implement common data collection.

9. Shift to systemic solutions for reducing environmental barriers in much the same way that anti-tobacco campaigns have shifted from assisting individual smokers with smoking cessation to advocating for smoke-free environments.

PROMOTE AND INITIATE RESEARCH

1. Establish standards/guidelines/policies for a "Code of inclusion" OR "Code of accessibility."

2. Develop a prototype for collecting evidence that assistive technology effects change in societal participation. Examples are the collection of DME and augmentative communication data regarding technology and participation, and related expenditures.

3. Conduct literature reviews/meta-analyses on current measures based on the participation concept, prior surveys on technology, and use-disuse/abandonment of technology.

4. Conduct studies to identify and develop emerging technologies.

5. Encourage NIH cohorts to include persons with disability and track their need for/use of technology; identify the need as well as which technology is actually awarded.

6. Apply public health methodologies to a review of existing environmental barriers data in an effort to target environmental interventions with the greatest potential impact.

7. Investigate the range of human functioning among the total population with implications for environmental design.

8. Investigate specific examples of environmental factors having an effect on the health, participation and quality of life of people with disabilities.

PUBLIC AND PROFESSIONAL EDUCATION

1. Strengthen the information center or clearinghouse for Standards and Guidelines of Accessibility of Facilities and Programs (NCPAD).

2. Provide for professional certification of facilities and individuals.

3. Raise awareness on the demand side; provide "how-to" information.

4. Promote programs and facilities development of alternate format access to information about health and wellness opportunities.

5. Highlight communities that are particularly effective in improving community environments.

6. Implement universal design principles in the curricula of schools of design, architecture, and planning.

7. Develop a public relations campaign, with the assistance of the National Ad Council, targeting attitudes toward people with disabilities. Incorporate the message that universal design is good for everyone while being especially helpful to people with disabilities in increasing participation and choice. Raise expectations of what people with disability can and should do.

8. Disseminate all public health material in multiple formats.

9. Expand the perspective of service providers to incorporate the broader environmental context.

10. Shift to systemic solutions for reducing environmental barriers in much the same way that anti-tobacco campaigns have shifted from assisting individual smokers with smoking cessation to advocating for smoke-free environments.

11. Address the issue that ADA is not in compliance in courtrooms. Often when a person with a disability has been selected to serve on a jury duty, they discover that the courtroom is not accessible.

PARTICIPATION/WORK

Objectives 6.8 (Employment parity) and 6.12 (Environmental barriers affecting participation)

For each of the following, specify the actions that need to be taken to launch such programs and put appropriate policies in place; establish priorities for action; and recommend the appropriate administrative and logistical support that will be needed to implement the strategic plan

DATA COLLECTION
Surveillance: Coordinate with agencies such as SSA and BLS to use data to monitor employment, income, and benefit levels of people with disabilities, including severe disabilities with higher risks for unemployment (e.g., persons with mental illness), and by race, ethnicity, gender, and education.

COALITION BUILDING
Work with other federal, state and local agencies, advocacy groups, and universities to increase social participation.

LEGISLATIVE INITIATIVES
1. Provide economic incentives (i.e., tax credits) to businesses to encourage hiring persons with disabilities.

2. Establish a stronger mandate to comply with ADA**.**

3. Eliminate disincentives to work by maintaining Medicaid/Medicare coverage under employment.

4. Obtain educational opportunities and support from ADA enforcement.

5. Revisit health care for persons with disabilities as a program of equity.

6. Increase enforcement of ADA.

7. Develop a support system during difficult economic times; that is, a system to protect people with disabilities from job loss when the economy contracts.

8. Develop model state legislation through the National Association of Insurance Commissioners.

9. Integrate health benefits and carve-outs with workers compensation administrators and SSDI, SSI.

10. Provide small group reinsurance for high-risk individual employees.

PUBLIC AND PROFESSIONAL EDUCATION
1. Provide educational programs ranging from an introduction to disability to how to provide reasonable accommodations to employers (e.g., brochures, American Management Association courses, Certified Employee Benefits Specialist [CEBS] courses).

2. Increase vocational, secondary and post-secondary educational opportunities through an incentive program for persons with disabilities and educational or training institutions.

3. Encourage vocational rehabilitation programs to emphasize preparing individuals for 21st century jobs.

<u>**CAREGIVERS/LONG-TERM CARE**</u>

Objective 6.7 (Congregate care of children and adults with disabilities)

For each of the following, specify the actions that need to be taken to launch such programs and put appropriate policies in place; establish priorities for action; and recommend the appropriate administrative and logistical support that will be needed to implement the strategic plan.

DATA COLLECTION
1. All states should have internal tracking systems and designate responsible agencies for reporting a common set of data on community/institutional services; grants should be available to assist those states without developed systems to establish systems more like those of exemplary states.

2. Determine the possibility for and costs of a national annual reporting system of key indicators.

3. Review data from states that have already achieved this objective to serve as models for others; that is, determine the "best practice" states.

COALITION BUILDING
Encourage partnerships among government, persons with disabilities, and their allies in changing the culture to view persons with disabilities as full and valued members.

LEGISLATIVE INITIATIVES
1. Ensure that dollars are attached to persons, not to beds or programs, and that people with disabilities and those they trust (family members, neighbors, friends, service providers) are controlling resources.

2. Federal and state governments must identify and remove existing disincentives to family and community living (e.g., losing health care when you work a "real" job).

3. The federal government should commit to a policy of people being able to "age in place" such that services come to people rather than making people move to where the services are provided.

4. Federal and state governments must develop commitments and policies to ensure an adequate workforce.

5. Any individual with a disability, or family with a disabled member, who is eligible for family or community support should receive those supports within a reasonable period (90 days).

6. The nation must develop the long-term financial commitment to funding long-term care, especially because aging baby boomers—both people with disabilities and caregivers—have needs that will dramatically increase in the years ahead.

PROMOTE AND INITIATE RESEARCH

1. Studies on reducing congregate care provide valuable advice on careful deinstitutionalization planning.

2. Study the characteristics, actions, policies, organizational structure, financing, etc. of leader states and communities, and the ways that these can be replicated.

PUBLIC AND PROFESSIONAL EDUCATION

1. Provide wider opportunities for individuals and families to use programs that support community and family living, including, but not limited to:
- Personal care options and other types of personal assistance and supported living
- Supported employment
- Family support (respite care, in-home support to families, specialized day care)
- Alternative family arrangements (shared parenting)
- Specialized foster care (supporting the concepts of permanency planning)
- Behavioral support and crisis response
- Accessible, affordable health care, health promotion, and prevention
- Individual service coordination (independent case management)
- Transition planning and supports

2. There is a need for better understanding and enforcement of accessibility laws throughout the US.

3. Some states have developed "road maps" to show how to achieve important community and family support objectives (e.g., Michigan has no children in congregate care). We need to highlight the states that have made progress in important areas, and provide technical assistance from leader states and communities to states that have further to go. Provide training, show how to shift the funds, and develop the collective will to follow the road map.

4. Support the establishment and expansion of graduate programs in disability studies in colleges and universities.

APPENDICES

APPENDIX I. —LEADING HEALTH INDICATORS
Healthy People 2010 Objectives that are Leading Health Indicators

Healthy People 2010 Objective (Short Text)	Healthy People 2010 Objective Number
■ *Physical Activity*	
Moderate physical activity in adults	22-2
Vigorous physical activity in adolescents	22-7
■ *Overweight and Obesity*	
Obesity in adults	19-2
Overweight and obesity in children and adolescents	19-3c
■ *Tobacco Use*	
Cigarette smoking by adults	27-1a
Cigarette smoking by adolescents	27-2b
■ *Substance Abuse*	
Alcohol and illicit drug use by adolescents	26-10a
Illicit drug use by adults	26-10c
Binge drinking by adults	26-11c
■ *Responsible Sexual Behavior*	
Responsible adolescent sexual behavior	25-11
Condom use by adults	13-6
■ *Mental Health*	
Treatment for adults with recognized depression	18-9b
■ *Injury and Violence*	
Deaths from motor vehicle crashes	15-15a
Homicides	15-32
■ *Environmental Quality*	
Ozone pollution exposure	8-1a
Exposure to environmental tobacco smoke	27-10
■ *Immunization*	
Fully immunized children aged 19 to 35 months	14-24
Flu and pneumococcal vaccination in high-risk adults	14-29a,b
■ *Access to Care*	
Persons with health insurance	1-1
Source of ongoing care	1-4a
Early prenatal care	16-6a

APPENDIX II. SYMPOSIUM WORKGROUP PARTICIPANTS
ALPHABETICAL LISTING OF NAMES

Mike Adams
Deborah Allen
Barbara Altman
Elena Andresen
Polly Arango
Richard C. Baron
Larry Burt
Cheryl Bushnell
Vincent A. Campbell
Stephen Corbin
Wendy Coster
John Crews
Juliana Cyril
Charles E. Drum
Dick Duncan
Alexandra Enders
G. Dean Ericson
Gail Finkel
Tony Fowler
William D. Frey
Jane Gay
Nedra Gillette
Yhetta Gold
David B. Gray
Harlan Hahn
Bryna Helfer
Richard Hemp
Gregg Howard
John Hough
Carol Hughes
Rosemary B. Hughes
Gail Hunt
Corinne Kirchner
Chris Kochtitzky
Gloria Krahn
Krista Kutash

Charlie Lakin
Donald J. Lollar
Larry Lorenzo
Jayne Lux
Michael Marge
Sharon Meek
Linda McClain
Suzanne McDermott
Suzanne Mintz
Susan E. Palsbo
Pat Puckett
Burton D. Pusch
James H. Rimmer
Allison (Sunny) Roller
Marcia Roth
Priscilla R. Sanderson
Donna Scandlin
Chrisann Schiro-Geist
Barbara Schwentor
Doug Schwentor
Thomas Seekins
Raymond Seltser
Rune J. Simeonsson
Marlene Simon
Lisa Sinclair
Camille Smith
Thomas Strax
Thomas E. Stripling
Patricia M. Sullivan
Sue Swenson
Denise Tate
JoAnn Thierry
Kent Waldrep
Lesa Walker
Gale Whiteneck
Bob Williams

APPENDIX III: SYMPOSIUM PARTICIPANTS BY WORKGROUP

Objective 6.1: Data

Mike Adams
Battelle
c/o DBDCDDH
Centers for Disease Control and Prevention
4770 Buford Hwy, F-34
Atlanta, GA 30341
Phone: 770-488-7154
mja1@cdc.gov

Barbara Altman
National Center for Health Statistics
Presidential Building
6525 Belcrest Road, P-08
Hyattsville, MD 20782
Phone: 301-458-4654
bea5@cdc.gov

Elena Andresen
Associate Profressor of Epidemiology
Department of Community Health
School of Public Health
St. Louis University
3663 Lindell Blvd.
St. Louis, MO 63108-3342
Phone: (314) 977-8130
(800) 782-6769
FAX: (314) 977-8150
andresen@slu.edu

Vincent A. Campbell
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
770-488-7684
vbc6@cdc.gov

William D. Frey
WESTAT
Senior Study Director
1650 Research Boulevard
Rockville, MD 20850
Phone: (301) 610-5198
FAX: (301) 251-8289
freyw1@westat.com

Corinne Kirchner
Director of Policy Research and Program
 Evaluation
American Foundation for the Blind
11 Penn Plaza
Suite 300
New York, NY 10001
Phone: (212) 502-7640
FAX: (212) 502-7773.
corinne@afb.net

Objective 6.2: Child Mental Health

Deborah Allen
Massachusetts Department of Public Health
250 Washington Street
Boston, MA 02108
Phone: (617) 624-5959
deborah.allen@state.ma.us

Bryna Helfer
Easter Seals
700 13th Street NW, Suite 200
Washington, DC 20005
Phone: 202-347-3066
bhelfer@opa.easter-seals.org

Krista Kutash
Associate Professor and Deputy Director
Research and Training Center for Children's
  Mental Health
Louis de la Parte Florida Mental Health
  Institute
University of South Florida
13301 Bruce B. Downs Blvd.
Tampa, FL 33612-3807
Phone: (813) 974-4661
FAX: (813) 974-6257
kutash@fmhi.usf.edu

Donald J. Lollar
National Center on Birth Defects and
  Developmental Disabilities
Centers for Disease Control and Prevention
4770 Buford Highway, F-34
Atlanta, GA 30341
Phone: (770) 488-7094
FAX: (770) 488-7156
dcl5@cdc.gov

Rune J. Simeonsson
University of North Carolina at Chapel Hill
North Carolina Office on Disability and
  Health
FPG Child Development Center
Sheryl-Mar Building, CB #8185
Chapel Hill, NC 27599-8185
Phone: (919) 966-6634
FAX: (919) 966-0862
rune_simeonsson@unc.edu

Patricia M. Sullivan
Center for Abused Children with Disabilities
Boys Town National Research Hospital
555 N. 30th Street
Omaha, NE 68131
Phone: (402) 498-1656
Fax: (402) 498-1654
sullivant@boystown.org

Objective 6.3: Adult Mental Health

John Hough
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: 770-488-7830
jph7@cdc.gov

G. Dean Ericson
Neuropsychologist and Rehabilitation
Psychologist
Shepherd Center
2020 Peachtree Street, NW
Atlanta, GA 30309
Phone: (404) 352-2020
FAX: 404-367-1236
dericson@mindspring.com

Jayne Lux
Practice Directorate
American Psychological Association
750 First Street, NE
Washington, DC 20002
Phone: (202) 336-5881
FAX: (202) 336-5797
jlux@apa.org

Suzanne McDermott
Associate Professor
University of South Carolina
  School of Medicine
Department of Family and Preventive Medicine
6 Richland Medical Park
Columbia, SC 29208
Phone: (803) 434-2445
FAX (803) 434-7529
suzanne.mcdermott@palmettohealth.org

Rosemary B. Hughes
Assistant Professor, Department of Physical
  Medicine & Rehabilitation
Associate Director, Center for Research on
  Women with Disabilities
Baylor College of Medicine
3440 Richmond Ave, Suite B
Houston, TX 77046
Phone: 713) 960-0505
Phone: (713) 961-3555
rhughes@bcm.tmc.edu

Thomas Seekins
Director, Research and Training Center
Attn: Morah Raynock
Rural U. of Montana
52 Corbin Hall
Missoula, MT 59812
Phone: (406) 243-2654
(406) 243-2349 (fax)
ruraldoc@selway.umt.edu

Objective 6.4: Social Participation

Stephen Corbin
Special Olympics, Inc.
1325 G Street, NW, Suite 500
Washington, DC 20005
Phone: (202) 824-0283
FAX: (202) 824-0397
scorbin@specialolymics.org

June Isaacson Kailes
Disability Policy Consultant
6201 Ocean Front Walk
Suite 2
Playa del Rey, CA 90293-7556
Phone: (310) 821-7080
FAX: (310) 827-0269
jik@pacbell.net
http://www.jik.com

Bryan Kemp
Director, Rehabilitation Research and
  Training Centers on Aging With a
  Disability
Rancho Los Amigos National Rehabilitation
  Center
7601 East Imperial Highway
Downey, CA 90242-3496
562 401-7402
bkemp@hsc.usc.edu

Burton D. Pusch
UAP Faculty, UAMS: Peds
501 Woodland Drive, Suite 210
Little Rock, AK 72201
Phone: (501) 682-9900
(501) 682-9901 (fax)
puschburtond@exchange.uams.edu

Objective 6.5: Emotional Support

Larry Lorenzo
700 Dooley
Almorgordo, NM 88310
Phone: (505) 434-9758
Cell: (505) 644-8651

Donna Scandlin
North Carolina Office on Disability and
 Health
Frank Porter Graham Child Development
 Center
University of North Carolina at Chapel Hill
521 South Greensboro Street
CB #8185
Chapel Hill, NC 27599-8185
Phone: (919) 966-0868
FAX: (919) 966-0862
donna_scandlin@unc.edu

Thomas E. Stripling
Senior Health Data Analyst
Paralyzed Veterans of America
801 - 18th Street, NW
Washington, DC 20006
Main phone: (800) 424-8200
Direct line: (202) 416-7668
FAX: (202) 331-1657
toms@pva.org

Denise Tate
Department of Rehabilitation Psychology
University of Michigan
Ann Arbor, MI
Phone: (734) 936-7052
FAX: (734) 763-0971
dgtate@umich.edu

JoAnn Thierry
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: 770-488-7097
jxt4@cdc.gov

Barbara Schwentor
Holland Community Hospital
Rehabilitation Services Department
602 Michigan Ave.
Holland, MI 49423
Phone: (616) 494-4119
FAX: (616) 669-3833
barbas@hoho.org

Objective 6.6: Life Satisfaction

Cheryl Bushnell
Massachusetts Department of Public Health
250 Washington St., 4th Floor
Boston, MA 02108-4619
Phone: 617-624-5967
cheryl.bushnell@state.ma.us

Cyndi Jones
The Center for an Accessible Society
2980 Beech Street
San Diego, CA 92102-1534
Phone: (619) 232-2727 ext. 111
FAX: (619) 234-3155
cjones@accessiblesociety.org

Allison (Sunny) Roller
Program Manager
Physical Medicine and Rehabilitation
University of Michigan Medical Center
IG202 University Hospital
1500 E. Medical Center Drive
Ann Arbor, MI 48109-0050
Phone: (734) 936-9474
(313) 763-0574 (fax)
elsol@mailgs2.pmr.med.umich.edu

Priscilla R. Sanderson
Director, American Indian Rehabilitation
  Research and Training Center
Arizona University Affiliated Program
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86011-5630
Phone: (520) 523-4791
FAX: (520) 523-9127
priscilla.sanderson@nau.edu

Doug Schwentor
Lakeshore Center for Independent Living
426 Century Lane
Holland, MI 49423
Phone: (616) 396-5326
FAX: (616) 396-3220
dougs@egl.net

Thomas Strax
Professor and Chair, Department of Physical
  Medicine and Rehabilitation
UMDNJ/RWJ Medical School
Medical Director
JFK/Johnson Rehabilitation Institute
65 James Street
Edison, NJ 08818
Phone: (732) 321-7070
tstrax@jfktlBOCVAN.com

Objective 6.7: Congregate Care

Harlan Hahn
717 11th Street
Santa Monica, CA 90402
Phone: (310) 395-5804
Alternate phone: (213) 740-8122
FAX: (310) 434-9214
hahnharlan@aol.com

Richard Hemp
University of Illinois at Chicago
Department of Disability and Human
Development
1640 West Roosevelt Road, CM/C626
Chicago, IL 60608-6904
Phone: (312) 413-1976
rickhemp@uic.edu

Charlie Lakin
U. of Minnesota, RTC on Community Living
212 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
Phone: (612) 624-6328
lakin001@umn.edu

Pat Puckett
Statewide Independent Living Council
1431-C McLendon Drive
Decatur, GA 30033
Phone: (770) 270-6860
FAX: (770) 270-5957
silcga@mindspring.com

Lisa Sinclair
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: (770) 488-7667
lvs4@cdc.gov

Sue Swenson
Administration on Developmental Disabilities
370 L'Enfant Promenade, 300F
Washington, D.C. 20447
Phone: 202 690-5806
sswenson@acf.dhhs.gov

Lesa Walker
Texas Department of Health
CSHCN Division
1100 West 49th Street
Austin, TX 78756-3179
512 458-7111 x2567
Lesa.Walker@TDH.state.TX.US

Objective 6.8: Employment

Richard C. Baron
Project Director
OMG Center for Collaborative Learning
1528 Walnut Street, Suite 805
Philadelphia PA 19102
Phone: (215) 732-2200
FAX: (215) 732-8123
rick@omgcenter.org

Larry Burt
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: 770-488-7081
lrb1@cdc.gov

Charles E. Drum
Oregon Office on Disability and Health
Oregon Institute on Disability and
  Development
Oregon Health Sciences University
PO Box 574
Portland, OR 97207-0574
Phone: (503) 494-8047
TTY: (503) 494-7373
FAX: (503) 494-6868
e-mail: drumc@ohsu.edu

Michael Marge
American Association of Health and Disability
449 Old Orchard Circle
Millersville, MD 21108
Phone: (410) 965-0149
(410) 965-3308 (fax)
mmarge@a-znet.com

Susan E. Palsbo
Associate Director
Center for Health & Disability Research
National Rehabilitation Hospital
MedStar Research Institute
1016 16th St. NW, Suite 400
Washington, DC 20036-5724
Phone: (202) 466-1904
FAX: (202) 466-1911
susan.e.palsbo@medstar.net

Chrisann Schiro-Geist
Professor and Director,
Disability Research Institute,
University of Illinois at Urbana-Champaign.
158 Rehabilitation Education Center
MC-575
1207 S. Oak Street
Champaign, IL 61820
Phone: (217) 265-0279
chrisann@uiuc.edu

Objective 6.9: Education

Polly Arango
Algodones Associates
PO Box 338
1452 Highway 313
Algodones, NM 87001
Phone: (505) 867-3159
FAX: (505) 867-5026
Polly@algodonesassociates.com

Wendy Coster
Chair, Department of Occupational Therapy
Sargent College of Health & Rehabilitation
  Sciences
Boston University
635 Commonwealth Avenue
Boston, MA 02215
Phone: (617) 353-7518
FAX: (617) 353-2926
wjcoster@bu.edu

Carol Hughes
Public Relations Officer
Center for Rehabilitation Technology
Georgia Institute of Technology
490 10th Street
Atlanta, GA 30318
Phone: (404) 894-4283
FAX: (404) 894-9320
carol.hughes@arch.gatech.edu

George Jesien
Executive Director
American Association of University Affiliated
Programs (AAUAP)
8630 Fenton Street, Suite 410
Silver Spring, MD 20910
Phone: (301) 588-8252
FAX: (301) 588-2842
gjesien@aauap.org

Marlene Simon
Associate Division Director
Research to Practice Division
Office of Special Education Programs
US Department of Education
330 C Street, SW; Switzer Bldg.,
  Room 3517
Washington, DC 20202-2641
Phone: (202) 205-9089
FAX: (202) 205-8105
marlene.simon@ed.gov

Camille Smith
Developmental Disabilities Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-15
Atlanta, GA 30341
Phone: (770) 488-7402
cas0@cdc.gov

Janet Valluzzi
ASPH Intern
George Washington University
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: (770) 488-7080
valluzzi@gwu.edu

Objective 6.10: ADA/Facilities

Dick Duncan
Center for Universal Design
College of Design, NCSU
 Box 8613
Raleigh, NC 27695-8613
Phone: 919 515 8557
rc_duncan@ncsu.edu

Jane Gay
Iowa Program for Assistive Technology
100 Hawkins Drive
Iowa City, IA 52242
Phone: (319) 356-4463
jane-gay@uiowa.edu

Mark Johnson
Shepherd Center
2020 Peachtree Street, NW
Atlanta, GA 30303
Phone: (404) 350-7490
FAX: (404) 350-7341
mark_johnson@shepherd.org

Mike Jones
Shepherd Center
2020 Peachtree Street, NW
Atlanta, GA 30303
Phone: (404) 352-2020
mike_jones@shepherd.org

Chris Kochtitzky
Office of Planning, Evaluation, and Legislation
National Center for Environmental Health
Centers for Disease Control and Prevention
4770 Buford Highway, F-29
Atlanta, GA 30341
Phone: (770) 488-7114
csk3@cdc.gov

Linda McClain
13 Las Huertas Road
Placitas, NM 87043
Phone: (505) 771-0821
24hiking@msn.com

James H. Rimmer
Associate Professor
Director, National Center on Physical
  Activity and Disability and
 the Center on Health Promotion Research
  for Persons with Disabilities
University of Illinois at Chicago
Department of Disability and Human
  Development
1640 West Roosevelt Road, M/C626
Chicago, IL 60608-6904
Phone: (313) 413-9651
FAX: (312) 355-4058
Pager: (312) 556-8915
jrimmer@uic.edu

Objective 6.11: Assistive Technology

Juliana Cyril
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: (770) 488-7426
FAX: (770) 488-7075
zdq4@cdc.gov

Alexandra Enders
University of Montana
Rural Institute on Disability
52 Corbin Hall
Missoula, MT
Phone: 406-243-2655
enders@selway.umt.edu

Nedra Gillette
American Occupational Therapy Foundation
4720 Montgomery Lane
PO Box 31220
Bethesda, MD 20824
Phone: (301) 652-2682
FAX: (301) 656-3620
ngillette@aotf.org

David B. Gray
Research Professor
Program In Occupational Therapy
Washington University School of Medicine
Campus Box 8505
4444 Forest Park Parkway
St. Louis, MO 63108
Phone: (314) 286-1658
FAX: (314) 286-1601
grayda@msnotes.wustl.edu

Gregg Howard
Vice President, Reimbursement and
  Disability Association Relations
Independence Technology
40 Technology Drive
Warren, NJ 07059
Phone: (908) 412-2210
FAX: (908) 412-2205
ghoward@indus.jnj.com

Kent Waldrep
President and CEO
Kent Waldrep National Paralysis Foundation
16415 Addison Road, Suite 550
Addison, TX 75001
Main: 1 (800) 925-2873
Phone: (972) 248-7100
FAX: (972) 248-7313
(877) SCI-CURE
1-800-925-2873
KWaldrep@KWnpf.org

Objective 6.12: Environmental Barriers

John Crews
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: (770) 488-7668
wzc0@cdc.gov

Gail Finkel
FG Consortium
205 - 270 Roslyn Road
Winnipeg, Manitoba
CANADA R3L 0H3
Phone: (204) 453-1294
FAX: (204) 453-6378
gfinkel@escape.ca

Yhetta Gold
FG Consortium
211 Montrose Street
Winnipeg, Manitoba
CANADA R3M 3L9
Phone: (204) 488-1121
FAX: (204) 488-9319
ymgold@pcs.mb.ca

Susan Kinne
Center for Disability Policy & Research
146 N. Canal Street
Suite 313
Seattle, WA 98103
Phone: (206) 685-4769
susaki@u.washington.edu

Gale Whiteneck
Research Director
Craig Hospital
3425 S. Clarkson
Englewood, CO 80110
Phone: (303) 789-8204
FAX: (303) 789-8441
gale@craig-hospital.org

Bob Williams
Deputy Assistant Secretary for Disability,
Aging, and Long Term Care
Department of Health and Human Services
424E.2 Humphrey Building
200 Independence Ave, SW.
Washington, DC 20201
Phone: (202) 690-6443
bobrw@bellatlantic.net

Objective 6.13: State Programs

Gail Hunt
National Alliance for Caregiving
4720 Montgomery Lane
Suite 642
Bethesda, MD 20814
Phone: (301) 718-8444
gailhunt.nac@erols.com

David Keer
Program Manager
US Department of Education
National Institute on Disability and
  Rehabilitation Research
330 C Street S.W.
Switzer Building Room 3431
Washington, D.C. 20202
Phone: (202) 205-5633
david.keer@ed.gov

Suzanne Mintz
National Family Caregivers Association
10400 Connecticut Avenue
Suite 500
Kensington, MD 20895
Phone: (301) 942 6430
FAX: (301) 942-2302
suzanne@nfcacares.org

Marcia Roth
North Carolina Office on Disability
  and Health
1928 Mail Service Center
Raleigh, NC 27699-1928
Phone: (919) 715-2505
FAX: (919) 733-2997
marcia.roth@ncmail.net

Joe Smith
Disability and Health Branch
Centers for Disease Control and Prevention
4770 Buford Highway, F-35
Atlanta, GA 30341
Phone: (770) 488-7082
jos4@cdc.gov

Norm White
Manager, Disability and Health Program
Injury and Disability Programs
Bureau of Health Promotion – KDHE
109 SW 9th, Suite 602, Mills Building
Topeka, KS 66612-1271
Phone: (785) -296-8060
FAX: (785) 296-8645
TDD: 1-800-332-6262
nwhite@kdhe.state.ks.us

Coleen Boyle
Director
Division of Birth Defects, Child
  Development, and Disability and Health
NCEH, CDC
4770 Buford Highway, F-34
Atlanta, GA 30341
Phone: (770) 488-7366
cab3@cdc.gov

Participants not assigned to a particular workgroup:

Raymond Seltser
Emeritus Dean
Emeritus Professor of Epidemiology
University of Pittsburgh Graduate School
  of Public Health
4701 Willard Avenue, Apt. 1714
Chevy Chase, MD 20815
Phone: (301) 652-4760
rseltser@email.msn.com

Tony Fowler
Deputy Director
Division of Birth Defects, Child Development, and Disability and Health
NCEH, CDC
4770 Buford Highway, F-34
Atlanta, GA 30341
Phone: (770) 488-7192
anf2@cdc.gov

Sharon Meek
992 Hearthstone Place
Stone Mountain, GA
Phone: 404-297-4642
slmeek@mindspring.com

APPENDIX IV: HEALTHY PEOPLE 2000 DISPARITY DATA TABLE I

Table 1. Identifies all *Healthy People 2000* objectives and data that address the health of people with disabilities and disparities [19 unduplicated (sub) objectives out of 319 possible objectives]. Highlighted objectives were continued in the *HP2010* plan.

Reference: U.S. Department of Health and Human Services. *Healthy People 2000 Review, 1998-99*. Washington, DC: U.S. Government Printing Office, June 1999.

No.	Objective	2000 Target	Ref. Year	Disability Status		Data Source	Data Agency
				Vith	Without		
1-2e	People w/disabilities 20+ years who are overweight	25%	1994	38%	35%	NHIS	CDC
1-5b	People w/disabilities who report *no* leisure-time physical activity	20%	1995	29%	23%	NHIS	CDC
6-5a	People w/disabilities who report adverse health effects from stress	40%	1995	49%	34%	NHIS	CDC
6-8	People w/disabilities who seek help in coping w/personal emotional problems	30%	1995	27%	19%	NHIS	CDC
21-2a	People w/disabilities who had a tetanus booster in last ten yrs.	none	1995	**_57%_**	56%	NHIS	CDC
21-2b	Women w/disabilities ages ≥65 who had a Pap test in past 3 yrs.	none	1995	50%	59%	NHIS	CDC
21-2c	Women w/disabilities ages ≥50 who had a breast/mammography screen in past 2 yrs.	none	1995	56%	69%	NHIS	CDC
6-6	*People w/mental disorders* who use community support programs	30%	1994	34.6%		NHIS	CDC
6-7	*People w/major depressive disorder* who obtain treatment	54%	1992	34.2%		NCS	U. of MI
8-3	Children w/disabilities who are enrolled in preschool	none	1991 1995	56% 63%		NEGP SHPPS	NCES, CDC
9-11	*Adults w/traumatic spinal cord injury* and their incidence of secondary conditions	20% better		No data in review		No data source	
17-2	*People w/diabetes or asthma* who experience activity limitations			Reported by income and race		NHIS	CDC
17-4	*People w/asthma* who experience activity limitations	10%	1996	19.6%		NHIS	CDC
17-5	*People w/chronic back conditions* who experience activity limitations	19%	1996	27.9%		NHIS	CDC
17-10	*People w/diabetes* who experience secondary conditions: blindness, perinatal mortality and morbidity, end stage renal disease, amputation			Reported by condition		Multiple sources	
17-14	*People w/chronic or disabling conditions* who receive patient education			Reported by condition and race		NHIS	CDC
17-23	*People w/diabetes* who received a dilated eye exam in past year	70%	1991	52%		NHANES	CDC
20-11a	Institutionalized *chronically ill* or elderly who receive pneumococcus vaccine	80%	1995	22%		NHIS	CDC
20-11b	Institutionalized *chronically ill* or elderly who receive Influenza vaccine	80%	1995	61%		NHIS	CDC

Key to the various fonts in Table 1:

Bold/Underline identifies data that indicate that people w/disabilities are doing equal or better than people wo/disabilities

This shade	identifies *HP2000* objectives not replicated in *HP2010*

Italics denote objective targeting a population w/a specific condition

APPENDIX V: HEALTHY PEOPLE 2010 DISPARITY DATA TABLE II

Table 2. Identifies all *Healthy People 2010* objectives and data that address the health of people with disabilities and disparities. [**207** unduplicated (sub) objectives out of 467 possible objectives]

Reference: U.S. Department of Health and Human Services. *Health People 2010.* 2nd ed. With Understanding and Improving Health, and Objectives for Improving Health. 2 Vols. Washington, DC: U.S. Government Printing Office, November 2000.

No.	Objective	2010 Target	Baseline Data			Data Source	Data Agency
			Ref. Year	Disability Status			
				With	Without		
1-1*	People w/disabilities under age 65 who have health insurance	100%	1997	85%	86%	NHIS	CDC
1-4a*	People w/disabilities of all ages who have a specific source of ongoing care	96%	1998	**90%**	87%	NHIS	CDC
1-4b	People w/disabilities ages 0-17 who have a specific source of ongoing care	96%	1998	**95%**	93%	NHIS	CDC
1-4c	People w/disabilities ages 18+ who have a specific source of ongoing care	96%	1998	**88%**	85%	NHIS	CDC
3-9b	Adults w/disabilities ages 18+ who use protective measures against skin cancer	75%	1998	**48%**	46%	NHIS	CDC
3-11a	Women w/disabilities ages 18+ who have *ever* received a Pap test	97%	1998	**96%**	93%	NHIS	CDC
3-11b	Women w/disabilities ages 18+ who have received a Pap test in preceding 3 yrs.	90%	1998	79%	81%	NHIS	CDC
3-12a	Adults w/disabilities age 50+ who have received a fecal occult blood test in preceding 2 yrs.	50%	1998	**39%**	35%	NHIS	CDC
3-12b	Adults w/disabilities age 50+ who have *ever* received a sigmoidoscopy	50%	1998	**42%**	36%	NHIS	CDC
3-13	Women w/disabilities age 40+ who have received a mammogram in preceding 2 yrs.	70%	1998	54%	68%	NHIS	CDC
5-2	People w/disabilities who are newly diagnosed with diabetes	2.5 per 1,000	1994-96	6.4 per 1,000	2.5 per 1,000	NHIS	CDC
5-3	People w/disabilities who are new and previously diagnosed with diabetes	25 per 1,000	1997	87 per 1,000	28 per 1,000	NHIS	CDC
5-4	Adults w/disabilities age >20 whose diabetes is diagnosed	80%	1991-94	66%	69%	NHIS	CDC
6-3	Adults w/disabilities who report sad feelings that interfere with activities	7%	1997	28%	7%	NHIS	CDC

No.	Objective	2010 Target	Baseline Data			Data	Data Agency
			Ref. Year	Disability Status			
				With	Without		
6-4	Adults w/disabilities who participate in social activities	100%	1997	95%	100%	NHIS	CDC
6-5	Adults w/disabilities who report sufficient emotional support	79%	1998	70%	79%	BRFSS	CDC
6-6	Adults w/disabilities who report satisfaction w/life	96%	1998	87%	96%	BRFSS	CDC
6-8	Adults w/disabilities ages 21-64 who are employed	82%	1994-95	52%	82%	SIPP	Bureau of Census
6-9	Children w/disabilities who are included in regular education programs	60%	1995-96	45%	100%	DANS	OSERS
7-1	Youth w/disabilities who completed high school	85%	1995	79%	86%	CPS	Bureau of Census
7-6	Employed people w/disabilities age 18+ who participated in employee-sponsored health promotion events	75%	1994	56%	62%	NHIS	CDC
7-12	People w/disabilities who participated last year in one organized health activity	90%	1998	12%	13%	NHIS	CDC
12-9	Adults w/disabilities who have high blood pressure	16%	1991-94	32%	27%	NHANES	CDC
12-10	Adults w/disabilities who have their high blood pressure under control	50%	1991-94	**20%**	16%	NHANES	CDC
12-11	Adults w/disabilities with high blood pressure who are taking action to control their blood pressure	95%	1998	**86%**	83%	NHIS	CDC
12-12	Adults w/disabilities who have had blood pressure measured in past 2 yrs.	95%	1998	**92%**	90%	NHIS	CDC
12-13	Adults w/disabilities who have reduced mean total blood cholesterol	199 mg/dL	1991-94	208 mg/dL	204 mg/dL	NHANES	CDC
12-14	Adults w/disabilities who have high total blood cholesterol	17%	1991-94	24%	19%	NHANES	CDC
12-15	Adults w/disabilities who have had blood cholesterol screening in last 5 yrs.	80%	1998	**69%**	66%	NHIS	CDC
14-27a	Adolescents w/ disabilities ages 13-15 w/3 or more doses of hepatitis B vaccine	90%	1997	46%	48%	NHIS	CDC

Objective		2010 Target	Baseline Data			Data Source	Data Agency
			Ref. Year	Disability Status			
				With	Without		
14-27b	Adolescents w/disabilities ages 13-15 w/2 or more doses of measles, mumps, rubella vaccine	90%	1997	**91%**	89%	NHIS	CDC
14-27c	Adolescents w/disabilities ages 13-15 w/1 or more doses of tetanus-diptheria booster	90%	1997	**94%**	92%	NHIS	CDC
14-29a*	Non-institutionalized adults with disabilities ages 65+ who are annually vaccinated against influenza	90%	1998	**63%**	60%	NHIS	CDC
14-29b*	Non-institutionalized adults w/disabilities ages 65+ who ever received a pneumococcus vaccine	90%	1998	**53%**	45%	NHIS	CDC
14-29c	Non-institutionalized adults w/ disabilities ages 18-64 who are annually vaccinated against influenza	60%	1998	**29%**	25%	NHIS	CDC
14-29d	Non-institutionalized adults ages 18-64 who *ever* received a pneumococcus vaccine	60%	1998	**18%**	10%	NHIS	CDC
19-1a	Women and men w/disabilities who are at a healthy weight	60%	1991-94	32%	41%	NHANES	CDC
19-1b	Women w/disabilities who are at a healthy weight	60%	1991-94	35%	45%	NHANES	CDC
19-1c	Men w/disabilities who are at a healthy weight	60%	1991-94	30%	36%	NHANES	CDC
19-2a*	Women and men w/disabilities who are obese	15%	1991-94	30%	23%	NHANES	CDC
19-2b	Women w/disabilities who are obese	15%	1991-94	38%	25%	NHANES	CDC
19-2c	Men w/disabilities who are obese	15%	1991-94	**21%**	22%	NHANES	CDC
19-10	Children and Adults w/disabilities ages 2+ who consume < 2,400 mg sodium per day	65%	1991-94	**18%**	16%	NHANES	CDC
19-11	Children and Adults w/disabilities ages 2+ who meet recommended daily Calcium	75%	1991-94	**44%**	44%	NHANES	CDC
19-12c	Women w/disabilities ages 12-49 who have iron deficiency	7%	1991-94	**4%**	12%	NHANES	CDC
21-4	Adults w/disabilities ages 65-74 who have all teeth extracted	20%	1997	34%	22%	NHIS	CDC
21-10	Children and adults who annually use the oral health care system	56%	1996	40%	45%	MEPS	AHRQ
22-1	Adults w/disability ages 18+ who engage in no leisure-time physical activity	20%	1997	56%	36%	NHIS	CDC

No.	Objective	2010 Target	Baseline Data			Data Source	Data Agency
			Ref. Year	Disability Status			
				With	Without		
22-2a*	Adults w/disabilities ages 18+ who are physically activity 30 minutes 5 days/wk	30%	1997	12%	16%	NHIS	CDC
22-2b*	Adults w/disabilities age 18+ who are physically activity 20 minutes 3 days/wk	30%	1997	23%	33%	NHIS	CDC
22-3	Adults w/disabilities age 18+ who engage in vigorous physical activity 20+ minutes 3 days/wk	30%	1997	13%	25%	NHIS	CDC
22-4	Adults w/disabilities age 18+ who engage in strengthening exercises	30%	1998	11%	18%	NHIS	CDC
22-5	Adults w/disabilities age 18+ who engage in activities that enhance or maintain flexibility	40%	1995	29%	31%	NHIS	CDC
27-1a*	Adult w/disabilities who smoke cigarettes	12%	1998	32%	23%	NHIS	CDC
27-1b	Adults w/disabilities who use spit tobacco	0.4%	1998	3.2%		NHIS	CDC
27-1c		12.%	1998	3.7%	2.3%	NHIS	
27-5	Adults w/disabilities who stopped smoking 1 day or longer in attempt to quit	75%	1998	**43%**	39%	NHIS	CDC
28-4 N=58	Children and teens w/disabilities age ≤17 who also have blindness or visual impairments	20 per 1,000	1997	92%	19%	NHIS	CDC

	Objective	Target	Baseline Data		Source	Data Agency
			Year	With		
1-16	Adults w/disabilities in nursing homes who are diagnosed with pressure sores	8 per 1,000	1997	16 per 1,000	NNHS	CDC
2-2	*Adults w/chronic joint symptoms* ages 18+ who have a limitation in activity	21%	1997	27%	NHIS	CDC
2-3	*Adults w/chronic joint symptoms* who have difficulty w/personal care	1.4%	1997	2%	NHIS	CDC
2-5	*Working-aged adults w/arthritis* who are employed	78%	1997	67%	NHIS	CDC
2-10	*Adults w/osteoporosis* ages 65+ who are hospitalized for vertebral fracture	14 per 10,000	1998	17.5 per 10,000 adults ages 65+	NHDS	CDC
2-11	*Adults w/chronic back conditions* ages 18+ who have an activity limitation	25 per 1,000	1997	32 per 1,000	NHIS	CDC
4-2	*People w/chronic kidney failure* who die from cardiovascular disease	52 per 1,000	1997	70 per 1,000	U.S. RDS	NIH
4-7	*People w/diabetes* who experience kidney failure	78 per million	1996	113 per million	U.S. RDS	NIH
5-10	*People w/diabetes* who experience lower-extremity amputation	5 per 1,000	1990	11 per 1,000	NHDS or NHIS, CDC	
6-7a	Adults w/disabilities who live in congregate care facilities	46,681	1997	93,362 adults	Survey of state DD Directors, U. of MN or State of the States Study, U. of IL	
6-7b	Children w/disabilities who live in congregate care facilities	0	1997	24,300 children	Survey of state DD Directors, U. of MN or State of the States Study, U. of IL	
18-4	*People w/serious mental illness* who are employed	51%	1994	43%	NHIS	CDC
18-9a	*Adults w/serious mental illness* ages 18-54 who are receiving treatment	17% better	1997	47%	Multiple data sources	NIH or SAMHSA
18-9b*	*Adults w/recognized depression* ages 18+ who are receiving treatment	17% better	1997	23%	NHSDA	NIH or SAMHSA
18-9c	*Adults w/schizophrenia* ages 18+ who are receiving treatment	17% better	1984	60%	NHSDA	NIH or SAMHSA
18-9d	*Adults w/anxiety disorder* ages 18+ who are receiving treatment	17% better	1997	38%	Multiple data sources	NIH or SAMHSA
24-1a	*Children w/asthma* under age 5 whose death is due to asthma	1 per million	1998	2.1 per million	NVSS	CDC

No.	Objective	Target	Baseline Data		Source	Data Agency
			Ref. Year	Disability Status		
				With		
24-1b	*Children w/asthma* ages 5-14 whose death is due to asthma	1 per million	1998	3.3 per million	NVSS	CDC
24-1c	*Youth and adults w/asthma* ages 15-34 whose death is due to asthma	3 per million	1998	5.0 per million	NVSS	CDC
24-1d	*Adults w/asthma* ages 35-64 whose death is due to asthma	9 per million	1998	17.8 per million	NVSS	CDC
24-1e	*Adults w/asthma* ages 65+ whose death is due to asthma	60 per million	1998	86.3 per million	NVSS	CDC
24-2a	*Children w/asthma* under age 5 who are hospitalized due to asthma	25 per 10,000	1998	45.6 per 10,000	NHDS	CDC
24-2b	*Children and adults w/asthma* ages 5-64 who are hospitalized due to asthma	8 per 10,000	1998	12.5 per 10,000	NHDS	CDC
24-2c	*Adults w/asthma* ages 65+ who are hospitalized due to asthma	10 per 10,000	1998	17.7 per 10,000	NHDS	CDC
24-3a	*Children and adults w/asthma* under age 5 who incur ER visits	80	1995-97	150 per 10,000	NHAMCS	CDC
24-3b	*Children and adults w/asthma* ages 5-65 who incur ER visits	50	1995-97	71 per 10,000	NHAMCS	CDC
24-3c	*Children and adults w/asthma* ages 65+ who incur ER visits	15 per 10,000	1995-97	29.5 per 10,000	NHAMCS	CDC
24-4	*People w/asthma* whose activity is limited due to their condition	10%	1994-96	20%	NHIS	CDC
24-6	*People w/asthma* who receive formal patient education	30%	1998	8.4%	NHIS	CDC
24-9 N=30	*Adults w/breathing problems* whose activity is limited due to their condition	1.5%	1997	2.2%	NHIS	CDC

No.	Objective	2010 Target	Baseline Data		Data Source	Data Agency
			Ref. Year	Disability Status		
				With		
1-6	Families of people w/disabilities who have problems obtaining health care	7%		DNA	MEPS	AHRQ
5-1	People w/disabilities with diabetes who receive formal diabetes education	60%		DNA	NHIS	CDC
7-3	People w/disabilities in college who receive health-risk behavior information	85%		DNC	NCHRBS	CDC
9-2	Women w/disabilities ages 15-44 who give birth within 24 mos of a previous birth	6%		DNC	NSFG	CDC
9-4	Women w/disabilities ages 15-44 who become pregnant despite use of reversible contraception	7%		DNC	NSFG	CDC
9-7	Young girls w/disabilities ages 15-17who become pregnant	43 per 1,000		DNC	Abortion Survey	Alan Guttmacher Institute
12-1	Adults w/disabilities whose deaths are due to coronary heart disease	166 per 100,000		DNC	NVSS	CDC
12-7	Adults w/disabilities whose deaths are due to stroke	48 per 100,000		DNC	NVSS	CDC
14-22a	Children w/disabilities ages 19-35 mos who receive 4 doses DtaP vaccine	90%		DNC	NIS	CDC
14-22b	Children w/disabilities ages 19-35 mos who receive 3 doses Hib vaccine	90%		DNC	NIS	CDC
14-22c	Children w/disabilities ages 19-35 mos who receive 3 doses Hep B vaccine	90%		DNC	NIS	CDC
14-22d	Children w/disabilities ages 19-35 mos who receive 1 dose MMR vaccine	90%		DNC	NIS	CDC
14-22e	Children w/disabilities ages 19-35 mos who receive 3 doses Polio vaccine	90%		DNC	NIS	CDC
14-22f	Children w/disabilities ages 19-35 mos who receive 3 1 dose Varicella vaccine	90%		DNC	NIS	CDC
14-24a*	Children w/disabilities ages 19-35 mos who receive all recommended vaccines for at least 5 yrs.	80%		DNC	NIS	CDC

No.	Objective	2010 Target	Baseline Data		Data Source	Data Agency
			Ref. Year	Disability Status		
				With		
14-26	Children w/disabilities under age 6 who participate in immunization registries	95%		DNC	Annual Immuniz. Program Reports	CDC
4-27d	Adolescents w/disabilities ages 13-15 w/1 or more doses of varicella vaccine	90%		DSU	NHIS	CDC
14-29e	Institutionalized adults age 18+ who are annually vaccinated against influenza	90%		DNA	NNHS	CDC
14-29f	Institutionalized adults age 18+ who have *ever* received pneumococcus vaccines	90%		DNA	NNHS	CDC
16-1a	Women w/disabilities who experience fetal deaths at 20+ weeks gestation	4.1 per 1,000 live births		DNC	NVSS	CDC
16-1b	Women w/disabilities who experience fetal/infant deaths during the prenatal period	4.5 per 1,000 live births		DNC	NVSS	CDC
16-1c	Women w/disabilities who experience infant deaths within year 1 of life	4.5 per 1,000 live births		DNC	NVSS	CDC
16-1d	Women w/disabilities who experience neonatal deaths (first 28 days of life)	2.9 per 1,000 live births		DNC	NVSS	CDC
16-1e	Women w/disabilities who experience post neonatal deaths	1.2 per 1,000 live births		DNC	NVSS	CDC
16-3a	Teens and youth w/disabilities ages 10-14 who die prematurely	16.8 per 100,000		DNC	NVSS	CDC
16-3b	Teens and youth w/disabilities ages 15-19 who die prematurely	39.8 per 100,000		DNC	NVSS	CDC
16-3c	Teens and youth w/disabilities ages 20-24 who die prematurely	49 per 100,000		DNC	NVSS	CDC
16-4	Women w/disabilities who experience maternal death	3.3 per 100,000 live births		DNC	NVSS	CDC
16-6a*	Women w/disabilities who received prenatal care in the first trimester	90% of live births		DNC	NVSS	CDC
16-6b	Women w/disabilities who received adequate prenatal care	90% of live births		DNC	NVSS	CDC

No.	Objective	2010 Target	Baseline Data		Data Source	Data Agency
			Ref. Year	Disability Status		
				With		
16-9a	Women w/disabilities who have a cesarean with their first birth	15% of live births		DNC	NVSS	CDC
16-9b	Women w/disabilities who have had a prior cesarean	63% of live births		DNC	NVSS	CDC
16-10a	Women w/disabilities who give birth to low birth weight infants	5%		DNC	NVSS	CDC
16-10b	Women w/disabilities who give birth to very low birth weight infants	0.9%		DNC	NVSS	CDC
16-11a	Women w/disabilities who give birth preterm	7.6%		DNC	NVSS	CDC
16-11b	Women w/disabilities who have preterm births at 32-36 weeks gestation	6.4%		DNC	NVSS	CDC
16-11c	Women w/disabilities who have preterm births - <32 weeks gestation	1.1%		DNC	NVSS	CDC
16-13	Mothers w/disabilities whose full-term infants use the back sleep position	70%		DNC	NISP	NIH
16-16a	Women w/disabilities ages 15-44 whose pregnancy begun with adequate folic acid intake	80%		DSU	NHANES	CDC
16-16b	Women w/disabilities ages 15-44 whose pregnancy begun with adequate median RBC folate level	220ng/ml		DNA	NHANES	CDC
16-17a	Pregnant women w/disabilities who drink alcohol	94%		DNC		SAMHSA
16-17b	Pregnant women w/disabilities who binge drink	100%		DNC		SAMHSA
16-17c	Pregnant women w/disabilities who use smoking/tobacco	99%		DNC	NVSS	CDC
16-17d	Pregnant women w/disabilities who use illicit drugs	100%		DNC		SAMHSA
16-19a	Mothers w/disabilities who breastfeed their babies early postpartum	75%		DNC	Mother's Survey	Abbot Laboratories
16-19b	Mothers w/disabilities who breastfeed their babies at 6 months	50%		DNC	Mother's Survey	Abbot Laboratories
16-19c	Mothers w/disabilities who breastfeed their babies at 1 year	25%		DNC	Mother's Survey	Abbot Laboratories

No.	Objective	2010 Target	Baseline Data		Data Source	Data Agency
			Ref. Year	Disability Status		
				With		
19-3a	Children and teens w/disabilities ages 6-11 who are overweight	5%		DSU	NHANES	CDC
19-3b	Children and teens w/disabilities ages 12-19 who are overweight	5%		DSU	NHANES	CDC
19-3c*	Children and teens w/disabilities ages 6-19 who are overweight	5%		DSU	NHANES	CDC
19-4	Low-income children w/disabilities under age 5 who have growth retardation	5%		DNC	PedNSS	CDC
19-5	Children and adults w/disabilities over age 2 who eat at least 2 daily servings of fruit	75%		DNC	CSFII	USDA
19-6	Children and adults w/disabilities over age 2 who eat at least 3 daily servings of green or orange vegetables	50%		DNC	CSFII	USDA
19-7	Children and adults w/disabilities over age 2 who eat at least 6 daily servings of grain products (3 are whole grains)	50%		DNC	CSFII	USDA
19-8	Children and adults w/disabilities over age 2 who consume <10% of calories from saturated fat	75%		DNC	CSFII	USDA
19-9	Children and adults w/disabilities over age 2 who consume <30% of calories from total fat	75%		DNC	CSFII	USDA
19-12a	Children w/ disabilities ages 1-2 who have iron deficiency	7%		DNC	NHANES	CDC
19-12b	Children w/ disabilities ages 3-4 who have iron deficiency	7%		DNC	NHANES	CDC
19-13	Low-income women w/disabilities in 3rd trimester of pregnancy who have anemia	20%		DNC	PregNSS	CDC
19-17a	All people w/disabilities with hyperlipidemia, cardiovascular disease or diabetes who receive office visits that include education related to diet and nutrition.	75%		DNC	NAMCS	CDC
19-17b	People w/disabilities w/hyperlipidemia who receive office visits that include education related to diet and nutrition.	75%		DNC	NAMCS	CDC

No.	Objective	Target	Baseline Data		Source	Data Agency
			Ref. Year	Disability Status		
				With		
19-17c	People w/disabilities w/cardiovascular disease who receive office visits that include education related to diet and nutrition.	75%		DNC	NAMCS	CDC
19-17d	People w/disabilities w/diabetes whose office visits include education related to diet and nutrition. Diabetes	75%		DNC	NAMCS	CDC
19-18	Households of people w/disabilities who have food security and reduced hunger	94%		DNC	CPS	DOC
20-1a	People w/disabilities ages ≥16 whose deaths are due to work-related injuries in all industry	3.2 per 100,00 workers		DNC	CFOI	BLS
20-1b	People w/disabilities ages ≥16 and deaths are due to work-related injuries in mining field	16.5 per 100,00 workers		DNC	CFOI	BLS
20-1c	People w/disabilities ages ≥16 whose deaths are due to work-related injuries in construction	10.2 per 100,00 workers		DNC	CFOI	BLS
20-1d	People w/disabilities ages ≥16 whose deaths are due to work-related injuries in transportation	8.3 per 100,00 workers		DNC	CFOI	BLS
20-1e	People w/disabilities ages ≥16whose deaths are from work-related injuries in agriculture, forestry, fishing industries	16.9 per 100,00 workers		DNC	CFOI	BLS
21-1a	Children w/disabilities ages 2-4 who have dental carries	11%		DNC	Multiple data Sources	
21-1b	Children w/disabilities ages 6-8 who have dental carries	42%		DNC	Multiple data Sources	
21-1c	Youth w/disabilities age 15 who have dental carries	51%		DNC	Multiple data Sources	
21-2a	Children w/disabilities ages 2-4 who have untreated dental decay	9%		DNC	Multiple data Sources	
21-2b	Children w/disabilities ages 6-8 who have untreated dental decay	21%		DNC	Multiple data Sources	

	Objective	Target	Baseline Data		Data Source	Data Agency
			Year	Disability Status With		
21-2c	Youth w/disabilities age 15 who have untreated dental decay	15%		DNC	Multiple data Sources	
21-2d	Adults w/disabilities ages 35-44 who have untreated dental decay	15%		DNC	NHANES and OHSNA	CDC and IHS
21-3	Adults w/disabilities, who have none of their teeth extracted from dental carries	42%		DNA	NHANES and OHSNA	CDC and IHS
21-5a	Adults w/disabilities ages 35-44 who have gingivitis	41%		DNA	NHANES and OHSNA	CDC and IHS
21-5b	Adults w/disabilities ages 35-44 who have periodontal disease	14%		DNA	NHANES and OHSNA	CDC and IHS
21-6	People w/disabilities w/oral whose pharyngeal cancer was detected early	50%		DNA	SEER	NIH
21-8a	Children w/disabilities age 8 who have dental sealants on their molars	50%		DNC	NHANES and OHSNA	CDC and IHS
21-8b	Youth w/disabilities age 14 who have dental sealants on their molars	50%		DNC	NHANES and OHSNA	CDC and IHS
27-6	Pregnant women w/disabilities who stop smoking	30%		DSU	NHIS	CDC
28-12	Children and youth w/disabilities under age 18 who visit doctor for otitis media	294 per 1,000		DNC	NAMCS and NHAMCS	CDC
N=84						

No.		2010 Target	Baseline Data		Data Source	Agency
			Ref. Year	Disability Status		
				With		
1-15	*People w/long term care needs* who have access to a continuum of services			Developmental	Multiple Sources	HCFA, CDC, AHRQ
2-1	*Adults w/chronic joint symptoms* who have fewer means days of severe pain			Developmental	BRFSS or NHIS	CDC
2-4	*Adults w/arthritis* ages 18+ with personal and emotional problems who seek help in coping			Developmental	NHIS or BRFSS	CDC
2-7	*Adults w/chronic joint symptoms* who have seen a health care provider			Developmental		
2-8	*People w/arthritis* who have had evidence-based education integrated into the management of their condition			Developmental		
5-9	*People w/diabetes* who have foot ulcers			Developmental		
6-11	People w/disabilities who report not having the assistive devices or technology they need			Developmental	NHIS	CDC
6-12	People w/disabilities who report environmental barriers			Developmental	NHIS	CDC
14-24b	Youth w/disabilities ages 13-15 who receive the recommended vaccines			Developmental	NIS	CDC
16-21	*Children with sickling hemoglobinopathies* age ≤4 who are hospitalized for life-threatening sepsis			Developmental	NHDS	CDC
16-22	Children w/special health care needs who have access to a medical home			Developmental	Title V Reporting System	HRSA
24-5	*People w/asthma* who have missed number of school or work days due to asthma			Developmental	NHIS	CDC
24-7a	*People w/asthma* who receive written asthma management plans from their provider			Developmental		
24-7b	*People w/asthma* with prescribed inhalers who receive instruction on how to use them properly			Developmental		
24-7c	*People w/asthma* who receive education about recognizing early signs and symptoms of asthma episodes and how to respond appropriately, including instruction on peak flow monitoring for those who use daily therapy			Developmental		

No.	Objective	2010	Baseline Data		Data	Data Agency
			Ref. Year	Disability Status		
				With		
24-7d	*People w/asthma* who receive medication regimens that prevent the need for more than one canister of short-acting inhaled beta agonist per month for relief of symptoms			Developmental		
24-7e	*People w/asthma* who receive follow-up medical care for long-term management of asthma after any hospitalization due to asthma			Developmental		
27-1d	Adults w/disabilities who use other tobacco products			Developmental		
28-5	*People w/diabetes* who experience visual impairment due to diabetic retinopathy			Developmental		CDC
28-6	*People with glaucoma* who experience visual impairment			Developmental		CDC
28-10a	*People w/visual impairments* who use rehabilitation services			Developmental		CDC
28-10b	*People w/visual impairments* who use adaptive devices			Developmental		CDC
28-13 **N=23**	*People w/hearing impairment* who have access to rehab services and technology			Developmental		CDC

No.	Objective	2010 Target	Baseline Data		Data Source	Data Agency
			Ref. Year	Disability Status		
				With		
6-10	Health and wellness programs and facilities that provide full access for people w/disabilities			Developmental	National Network of Independent Living Centers	
6-13b	Tribes that have public health surveillance and health promotion programs for people w/disabilities and their care-givers	Total coverage		Developmental	NCBDDD, Disability and Health Program	CDC
17-3	Primary care providers, pharmacists and health care professionals who routinely review all newly prescribed and over-the counter medicines w/patients age 65+			Developmental	SPDIU or PSUMERI	AARP
23-5*	**Leading health- and health status-indicators** and priority data needs for which data are available at the tribal, state and local levels			Developmental	NCHS	CDC or IHS
	Establish state surveillance systems or programs to track asthma-related deaths, illness, disability, occupational and environmental factors			Developmental	CSTE and PHF Surveys	ASPH
6-1	Healthy People surveillance instruments that contain standardized questions identifying people w/disabilities	100%	1999	0%	NCBDD, Disability and Health Program	CDC
6-13a	States and DC that have public health surveillance and health promotion programs for people w/disabilities and their caregivers	Total coverage		14 States	NCBDDD, Disability and Health program	CDC
16-23	Territories and states that have service systems for children w/special health needs	100%	1997	15.7%	Title V Reporting System	HRSA
21-15	States and DC that have a system for recording and referring children w/craniofacial anomalies to rehabilitation teams		1997	23 states & DC	State Dental Directors	IL State Health Dept.
21-16	State and DC that have an oral and craniofacial health surveillance system	All	1999	0	ASTDD	

	Objective	Target	Baseline Data			Data Source	Data
			Ref. Year	Disability Status			
				With	Without		
23-4	Population-based HP2010 objectives for which national data are available for the specified populations	100%				NCHS	CDC
23-6 N=12	Healthy People objectives that are tracked at the national level every 3 yrs	100%	2000	82%		NCHS	CDC

Key to the various fonts in Table 2:

Bold/Underline identifies data that indicate that people w/disabilities are doing equal or better than people wo/disabilities

*asterisks denote objectives specified as Leading Health Indicators

italics denote objective targeting a population w/a specific condition

This shade	denotes objectives targeting public, government entities or systems, not people

APPENDIX VI: GLOSSARY

AAMC – Association of American Medical Colleges
AAP – American Academy of Pediatrics
AAPD – American Association of People with Disabi4lities
AARP – American Association of Retired Persons
AASA – American Association of School Administrators
AAUAP – American Association for University Affiliated Programs for Persons with
  Developmental Disabilities
ACA – Amputee Coalition of America
Access Board – The US Architectural and Transportation Barriers Compliance Board
ACS – American Cancer Society
ACTE – Association for Career and Technical Education
ADA – Americans with Disabilities Act
ADA – American Dental Association
ADAPT–American Disabled for Attendant Programs Today
ADLs – Activities of Daily Living
AED – Academy for Educational Development
AFT – American Federation of Teachers
AHA – American Heart Association
AHRQ – Agency for Healthcare Research and Quality (formerly, the AHCPR, Agency for
  Health Care Policy and Research)
AIA – American Institute of Architects
ALA – American Lung Association
AMA – American Medical Association
AMI – Alliance for the Mentally Ill
AOTA – American Occupational Therapy Association
APA – American Planning Association
APA – American Psychological Association
APHA – American Public Health Association
APRIL – Association of Programs in Rural Independent Living
APTA – American Physical Therapy Association
Arc – See: The Arc
ASA – American Society on Aging
ASCD – Association for Supervision and Curriculum Development
ASHA – American Speech-Language-Hearing Association
ASPH – Association of Schools of Public Health
ASTDD – Association of State and Territorial Dental Directors
AT – Assistive technology
ASTHO – Association of State and Territorial Health Officers
ATAP – Assistive Technology Act Project
BIA – Bureau of Indian Affairs
BLS – Bureau of Labor Statistics
BRFSS – Behavioral Risk Factor Surveillance System

CAHPS – Consumer Assessment of Health Plans
CARF – The Rehabilitation Accreditation Commission
CASE – Council of Administrators of Special Education
CCD – Consortium for Citizens with Disabilities
CCSSO – Council of Chief State School Officers
CDC – Centers for Disease Control and Prevention
CEBS – Certified Employee Benefits Specialist program
CEC – Council for Exceptional Children
CESD – Center for Epidemiologic Studies - Depression
CFOI – Census of Fatal Occupational Injuries
CGCS – Council of Great City Schools
CHIEF – Craig Hospital Inventory of Environmental Factors
CHIP – Children's Health Insurance Program
CILs – Centers for Independent Living
CPG – cardiovascular treadmill test
CPS – Current Population Survey, US Bureau of the Census
CSAVR – Council of State Administrators of Vocational Rehabilitation
CSFII – Continuing Survey of Food Intake by Individuals
cshcn – children with special health care needs, as they are referred to generically
CSHCN – Children with Special Health Care Needs, bona fide program of MCHB
CSTE – Council of State and Territorial Epidemiologists
CVD – cardiovascular disease
DALYs – Disability Adjusted Life-Years
DANS – Data Analysis System
DBTACs – Disability and Business Technical Assistance Centers
DD – Developmental Disabilities
DDC – Developmental Disabilities Councils
DHB – Disability and Health Branch
DHHS – Department of Health and Human Services
DME – durable medical equipment
DNA – Data Not Analyzed
DNC – Data Not Collected
DOE – Department of Education
DOI – Department of Interior
DOJ – Department of Justice
DOL – Department of Labor
DOT – Department of Transportation
DPI – Disabled People International (Canada)
DREDF – Disability Rights Education and Defense Fund
DSU – Data Statistically Unreliable
DUI trust funds – Driving under the influence; chemical testing trust funds
EAP – Employee Assistance Programs
EOC – Equal Opportunity Commission
EPSDT – Early Periodic Screening, Diagnosis and Treatment

FAPE – free appropriate public education
FDA – Food and Drug Administration
FES – Functional electrical stimulation
FIM – Functional Measure of Independence
FMAP – Federal Medical Assistance Percentage Handicaps)
HCBS – Medicaid Home and Community Based Services
HCFA – Health Care Financing Administration
HEDIS – Health Plan Employer Data and Information Set
HMO – health maintenance organization
HP 2010 – Healthy People 2010
HUD – Department of Housing and Urban Development
IADLs – Instrumental Activities of Daily Living
IAFP – International Association of Fitness Professionals
ICC – Interagency Coordinating Councils (there are federal, state and county ICCs
ICF – International Classification of Functioning, Disability, and Health/may also be referred to
    as ICFDH or ICIDH-2 (International Classification of Impairments, Disabilities, and
    Health
IDEA – Individuals with Disabilities Education Act
IEP – Individualized Education Program
IHS –Indian Health Services
ILIAD – The IDEA Local Implementation by Local Administrators (ILIAD) Partnership
IRS – Internal Revenue Service
JCAHO – Joint Commission on Accreditation of Healthcare Organizations
La Raza – Hispanic Health Group
LEA – local education agency
LHI – leading health indicator
LRE – In IDEA, LED refers to the requirement of providing for students with disabilities an
    education in the "least restrictive environment." The language used is a "LRE provision"
    or "LRE requirement."
LS – life satisfaction
LTD – long-term disability
MCHB – Maternal and Child Health Bureau
MCO – managed care organization
MEPS – Medical Expenditure Panel
MiCASSA – Medicaid Community Attendant and Support Services Act
MMWR – Morbidity and Mortality Weekly Report
MR – mental retardation
MSA – Metropolitan statistical area levels
NAACP – National Association for the Advancement of Colored People)
NABE – National Association for Bilingual Education
NABSE – National Alliance of Black School Educators
NACCHO – National Association of City and County Health Officials
NADDC – National Association of Developmental Disabilities Councils
NAEPP – National Asthma Education and Prevention Program

NAESP – National Association of Elementary School Principals
NAIC – National Association of Insurance Commissioners
NAMCS – National Ambulatory Medical Care Survey
NAMI – National Association of Mental Impairments
NAPVI – National Association for Parents of the Visually Impaired
NASA – National Aeronautics and Space Agency
NASDSE – National Association of State Directors of Special Education
NASN – National Association of School Nurses
NASP – National Association of School Psychologists
NASSP – National Association of Secondary School Principals
NASTHO – National Association of State and Territorial Health Officials
NCAI – National Congress of American Indians
NCBDDD – National Center on Birth Defects and Developmental Disabilities
NCC – National Council of Churches
NCD – National Council on Disability
NCDDR – National Center for the Dissemination of Disability Research
NCES – National Center for Educational Statistics
NCHRBS – National College Health Risk Behavior Survey
NCHS – National Center for Health Statistics
NCIL – National Council on Independent Living
NCPAD – National Center on Physical Activity and Disability
NCQA – National Council on Quality Assurance
NCS – National Comorbidity Survey
NCSL – National Conference of State Legislators
NEA – National Education Association
NEGP – National Education Goals Panel
NGA – National Governors Association
NGO – Non-governmental organization
NHAMCS – National Hospital Ambulatory Medical Care Survey
NHANES – National Health and Nutrition Examination Survey
NHDS – National Hospital Discharge Survey
NHIS – National Health Interview Survey
NICHD – National Institute of Child Health and Human Development
NIDDK – The National Institute of Diabetes and Digestive and Kidney Diseases
NIDRR – National Institute of Disability and Rehabilitation Research
NIEA – National Indian Education Association
NIH – National Institutes of Health
NIHB – National Indian Health Board
NILC – National Independent Living Council
NIMH – National Institute of Mental Health
NINDS – National Institute of Neurological Disorders and Strokes
NIS – National Immunization Survey
NISP – National Infant Sleep Position Study
NLTS-2 – National Longitudinal Transition Study

NNHS – National Nursing Home Survey
NOD – National Organization on Disability
NOW – National Organization of Women
NRHCHDR – National Rehabilitation Hospital Center for Health and Disability Research
NSBA – National School Board Association
NSF – National Science Foundation
NSFG – National Survey of Family Growth
NTRS – National Therapeutic Recreation Society
NVSS – National Vital Statistics Survey
ODPHP – Office of the Disease Prevention and Health Promotion
OHSNA – Oral Health Survey of Native Americans
OMB – Office on Management and Budget
OSEP – Office of Special Education Programs
OSERS – Office of Special Education and Rehabilitative Services
PACER – Parent Advocacy Coalition for Educational Rights
PAS – Personal Assistance Services
PedNSS – Pediatric Nutrition Surveillance Survey
PHF – Public Heath Foundation
PPO – preferred provider organization
PregNSS – Pregnancy Nutrition Surveillance Survey
PSUMERI – Physician Survey Under the Medication Error Reduction Initiative
PTA – Parent-teachers associations
PTI – Parent Training and Information Centers
PTO – Parent-teachers organizations
PWMI – People with Mobility Impairments
QEM – Quality Education for Minorities Network
QOL – quality of life
RCS – Respite Care Services
RESNA – Rehabilitation Engineering and Assistive Technology Society of North America
RFP – request for proposal
RI – Rehabilitation International
RN – registered nurse
RSA – Rehabilitation Services Administration
RWJF – Robert Wood Johnson Foundation
SAMSHA– Substance Abuse and Mental Health Services Administration
SBA – Small Business Administration
SCI – spinal cord injury
SED – In IDEA, SED refers to a "serious emotional disturbance." IDEA also uses the term
        "emotional disturbance" (or ED) to refer to the same population.
SEELS – Special Education Elementary Longitudinal Study
SEER – Surveillance Epidemiology and End Results
SET – Special Education Technology
SGA – substantial gainful allowance (for employment)
SHPPS – School Health Policies and Programs Study

SILC – State Independent Living Council
SIPP – Survey of Income and Program Participation
SOPHE – Society of Public Health Educators
SPDIU – Survey of Prescription Drug Issues and Usage
SSA – Social Security Administration
SSDI – Social security disability income
SSI – Social security insurance
TBI – traumatic brain injury
The Arc – (formerly) The Association for Retarded Citizens
Title V – Children with Special Needs Act
UAP – University Affiliated Programs
UCPA – United Cerebral Palsy Association
URAC – American Accreditation HealthCare Commission
USDA – United States Department of Agriculture
USRDS – United States Renal Data System
VA – Veterans Administration
VR – Vocational rehabilitation
WBGH – Washington Business Group on Health
WHO – World Health Organization
YHL – Years of Health Lost
YMCA – Young Men's Christian Association
YRBS – Youth Risk Behavior Survey